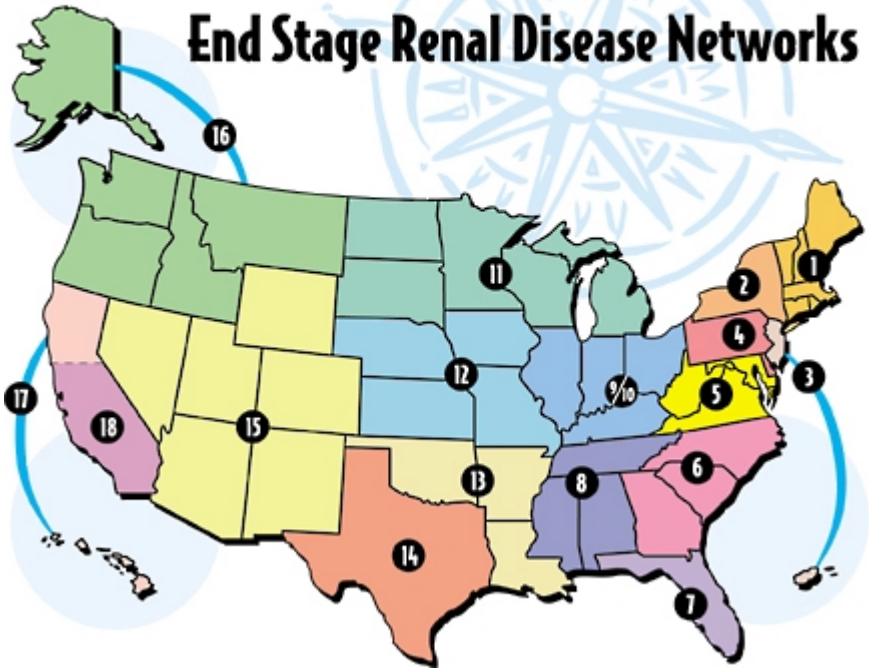
SUMMARY REPORT of the End Stage Renal Disease (ESRD) Networks' Annual Reports 2001



ESRD Networks are required by contract with the Centers for Medicare & Medicaid Services (CMS) to submit an Annual Report covering their activities during each calendar year. This Report summarizes those Annual Reports and is submitted to CMS as a contract deliverable by the Forum Clearinghouse of ESRD Networks. This document covers the time period of January 1, 2001, through December 31, 2001.

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SUMMARY REPORT
of the
End Stage Renal Disease (ESRD)
Networks' Annual Reports

2001

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EXECUTIVE SUMMARY

The Medicare End Stage Renal Disease (ESRD) Program, a national health insurance program for people with end-stage renal disease, was established in 1972 with the passage of Section 299I of Public Law 92-603. Congress gave much attention to this program and in 1977, modifications to the ESRD program were passed in Public Law 95-292. H.R. 8423 was designed to encourage self-care dialysis and kidney transplantation and clarify reimbursement procedures in order to achieve more effective control of the costs of the renal disease program. This legislation also authorized the establishment of ESRD Network areas and Network organizations, consistent with criteria determined by the Secretary of Health and Human Services (formerly the Department of Health, Education, and Welfare). The legislation mandated 32 geographic areas and organizations, but in 1987 Congress reduced the number to the existing 18 Networks (see inside front cover.)

The Centers for Medicare & Medicaid Services (CMS) contracts with the 18 ESRD Network Organizations to provide federally established services under the Medicare program. The Networks are not-for-profit organizations, led by volunteer boards and committees comprised of nephrology patients and professionals. CMS outlines the broad expectations for Networks and specifies projects and tasks in the ESRD Statement of Work (SOW). The ESRD Networks manage a computerized patient registry system, assure quality of care through continuous quality improvement methodology and data analysis, provide community education, and process beneficiary complaints.

All ESRD Networks are members of the Forum of ESRD Networks, which is a not-for-profit organization that advocates on behalf of its membership and coordinates projects and activities of mutual interest to ESRD Networks. The Forum facilitates the flow of information and advances a national quality agenda with CMS and other renal organizations. This Report, which summarizes the annual reports submitted by these 18 Network organizations for calendar year 2001, is prepared in the Forum Clearinghouse Office under CMS contract 500-00-NW14.

The ESRD Statement of Work outlines four goals to provide direction to the national ESRD Network program. These goals outline the basic functions of the ESRD Networks and are used to direct the Networks' daily activities. Each Network customizes its activities to meet and exceed CMS' expectations.

GOAL ONE: IMPROVING THE QUALITY OF HEALTH CARE SERVICES AND QUALITY OF LIFE FOR ESRD BENEFICIARIES

The Networks serve as liaisons between CMS and ESRD providers, and also between providers and the ESRD patients under their care. CMS, providers, and patients all have a vested interest in achieving optimal treatment, and the Networks serve as a vital link in the quality chain. Network organizations accomplish their quality mission by:

1. Collecting and validating patient-specific data;
2. Distributing data feedback reports for facilities to use in improving care;
3. Conducting quality improvement projects and activities focused on specific areas of care;
4. Providing professional educational materials and workshops for facility staff;
5. Providing patient educational materials and workshops to facilities and directly to patients; and,
6. Offering technical assistance to dialysis and transplant facilities.

Selected findings (based on 2001 data) from the 2002 ESRD Clinical Performance Measures (CPM) Project are highlighted below. Important improvements in adequate therapy and anemia management have been realized since the onset of this project:

- Adequacy of Dialysis: Hemodialysis - Mean URRs have increased each year that the CPM project has been conducted, from 62.7% in 1993 to 84% in 2001.
- Adequacy of Dialysis: Peritoneal Dialysis - During the study period (October 2001 - March 2002) an estimated 86% of patients sampled had at least one measured total solute clearance for urea and creatinine, which is an increase from 66% in 1995. Sixty-eight percent (68%) of continuous ambulatory peritoneal dialysis (CAPD) patients had both a mean weekly Kt/V V ≥ 2.0 and creatinine clearance ≥ 60 L/wk/1.73m2, which shows no change from the previous observation period.
- Nutritional Status: Serum Albumin – Hemodialysis: The percent of patients with *optimal* mean serum albumin values ≥ 3.7 (BCP) or 4.0 (BCG) in 1999 was 36%, compared to 27% in 1993.
- Nutritional Status: Serum Albumin – Peritoneal Dialysis: The percent of patients with *optimal* mean serum albumin values ≥ 3.7 (BCP) or 4.0 (BCG) was 19%.
- Anemia Management: Hemodialysis - In 2001, the proportion of patients with a hemoglobin ≥ 11 was 76%, compared to 59% in 1998.
- Anemia management: Peritoneal Dialysis - 76% of patients had a mean hemoglobin of ≥ 11 gm/dL, compared to 61% in the 1998-1999 study period.
- Vascular Access: Hemodialysis - Thirty-one (31%) of prevalent Hemodialysis patients dialyze by A-V fistula compared to 40% recommended by K/DOQI. Nineteen (19%) of prevalent patients had dialyzed by catheter for 90 or more days, representing a 9% improvement gap over the 10% recommended by K/DOQI.

Quality Improvement Projects

The ESRD Network contracts with CMS require implementation of at least two Quality Improvement Projects (QIPs) during the three-year contract period. These are in-depth projects for which CMS prescribes the format. These projects must address an area of care for which clinical performance measures and indicators have been developed, and the proposals must be submitted to CMS for approval prior to implementation. Each Network defines the opportunity for improvement, employs both outcome and process indicators, prepares a project design and methodology that supports statistical analysis, proposes intervention activities, and includes an evaluation mechanism. For 2001, CMS requested all Networks conduct a QIP on vascular access while work continued on the 2000 QIP on Adequacy of Dialysis. A brief overview and status of the QIP projects including vascular access are described in this Summary.

GOAL TWO: IMPROVING DATA REPORTING, RELIABILITY, AND VALIDITY BETWEEN ESRD FACILITIES/PROVIDERS, NETWORKS, AND CMS

To accomplish the second goal, Networks utilize both internal and external databases to track various data elements. Data reporting is an essential function of the Networks. Accurate data collection has a two-fold purpose:

1. Aids the Networks by providing a look at issues facing the regional ESRD population and a check system to measure facility accuracy and timeliness; and
2. Provides the national ESRD data system with accurate data to support quality improvement initiatives, CMS policy decisions, and the USRDS research activities.

The need to standardize each ESRD Network's data system was recognized by both CMS and the Networks. The Southeastern Kidney Council (Network 6) was awarded a contract in 1997 to design, develop, and install the Standard Information Management System (SIMS). It provides communication and data exchange links among the Networks, CMS, and other segments of the renal community to support quality improvement activities that relate to the treatment of ESRD. SIMS allows each Network to support and maintain its own database to store patient-specific information and information on ESRD-related events. On a broad level, these databases maintain demographic data as well as track patient transactions such as changes in modality, facility, transplant status, and/or death. In this manner, Networks are able to maintain accurate counts of patients within their area. The information tracked within Network databases is collected from the ESRD provider through the Medical Evidence Report Form (CMS 2728), the Death Notification Form (CMS 2746), patient event tracking forms, and facility rosters. In 2001, the Networks processed 100,468 CMS Form 2728s and 68,981 CMS Form 2746s for a total of 169,449 data forms processed.

GOAL THREE: ESTABLISHING AND IMPROVING PARTNERSHIPS AND COOPERATIVE ACTIVITIES AMONG AND BETWEEN ESRD NETWORKS, QUALITY IMPROVEMENT ORGANIZATIONS, STATE SURVEY AGENCIES, AND ESRD PROVIDERS/ FACILITIES

Networks are actively involved with both quality-related and renal-related organizations to facilitate cooperation and joint ventures. Each Network creates unique partnerships with organizations to help provide better care for the ESRD patient population, including renal groups, professional organizations, dialysis corporations, and pharmaceutical companies. The 2001 Annual Meeting for CMS and the ESRD Networks drew representatives from CMS, Networks (data, quality, patient services, and executive staff), as well as many Network Medical Review Board Chairs to discuss issues impacting the ESRD Networks. Other activities in 2001 included the implementation of the patient safety initiative, Phase I in the ESRD Program, reinvigorated partnerships with renal community members such as NKF and AAKP, and the updating of the New Patient Orientation Packet materials for Year Two of the project.

GOAL FOUR: EVALUATING AND RESOLVING PATIENT GRIEVANCES

Networks are responsible for evaluating and resolving patient grievances. Each Network has a formal grievance resolution protocol, which is approved by CMS. A formal beneficiary grievance is a complaint alleging that ESRD services did not meet professional levels of care. The formal grievance process requires the Network to conduct a complete review of the information and an evaluation of the grievance, which may require the involvement of a Grievance Committee and/or the Medical Review Board. During 2001, Networks processed 70 formal beneficiary grievances in comparison to 79 in 2000.

During 2001, Networks studied the issue of "challenging patients" defined by a number of Networks as cases in which a patient presents to a clinic and acts out in a violent manner or is verbally abusive or threatening. Although this is not a new issue, the Networks indicate that this is a growing problem that involves many dynamics. Many Networks continue to provide workshops and written material focusing on this issue and spend a great deal of staff time providing consultation to the clinics in an effort to deal with this issue.

This Report summarizes highlights of the ESRD Networks' 2001 activities. Internet addresses are provided for additional information about the ESRD Networks and the ESRD program. All Network web sites can be accessed through the home page of the Forum Clearinghouse Office, www.esrdnetworks.org.

SUMMARY REPORT

INTRODUCTION

The Medicare End Stage Renal Disease (ESRD) Program, a national health insurance program for people with end-stage renal disease, was established in 1972 with the passage of Section 299I of Public Law 92-603. Congress gave much attention to this program and in 1977, modifications to the ESRD program were passed in Public Law 95-292. H.R. 8423 was designed to encourage self-care dialysis and kidney transplantation and clarify reimbursement procedures in order to achieve more effective control of the costs of the renal disease program. This legislation also authorized the establishment of ESRD Network areas and Network organizations, consistent with criteria determined by the Secretary of Health and Human Services (formerly the Department of Health, Education, and Welfare). The legislation mandated 32 geographic areas and organizations, but in 1987 Congress reduced the number to the existing 18 Networks (see inside front cover). This Report summarizes the annual reports submitted by these 18 Network organizations for calendar year 2001.

ESRD POPULATION & CHARACTERISTICS

Although the ESRD population is less than 1% of the entire U.S. population, it continues to increase at a rate of 3% per year and includes all races, age groups, and socioeconomic standings. Because the ESRD Network organizations cover all 50 states plus the District of Columbia, Puerto Rico, the Commonwealth of the Northern Mariana Islands, Guam, and the U.S. Virgin Islands, much variation is seen in both the overall population and the ESRD population. While California (Networks 17 & 18) had the largest state population, Network 6 had the largest population on dialysis. At the end of 2001 there were 288,805 patients being dialyzed and 96,657 new ESRD patients (Appendix A).

Table 1

ESRD INCIDENCE RATES BY NETWORK

Calendar Year 2001

Network	Initiated ESRD Therapy	General Population	Incidence Rate Per Million Population
1	3,658	13,922,517	263
2	6,646	18,976,457	350
3	4,463	12,371,085	361
4	4,827	13,083,315	369
5	5,907	14,755,404	400
6	7,933	20,247,778	392
7	6,006	16,396,515	366
8	4,956	12,981,041	382
9	7,153	31,475,394	227
10	4,274	12,419,293	344
11	6,736*	21,756,065	304
12	4,028	12,959,000	311
13	4,152	10,617,617	391
14	7,216	20,700,000	349
15	4,218	15,976,000	264
16	2,693	12,321,171	219
17/18 **	11,791	35,379,438	333
Total	**96,657**	**296,338,090**	**326**

Source: Networks 1-18 Annual Reports, 2001

* includes newly diagnosed chronic ESRD patients from out of Network

**Networks 17 and 18 have been combined to incorporate the state of California. Hawaii and American territories are included.

AGE

In 2001 forty-five (45) percent of the ESRD patients were between the ages of 60 and 79 and the pediatric population remained relatively small with less than one percent of the ESRD population under 20 years old (Table 2). This same age distribution can be seen in the incident population (Appendix B). These distributions have remained the same over the past four years.

Table 2
PREVALENCE OF DIALYSIS POPULATION
BY AGE AND NETWORK WHERE TREATED
December 31, 2001

Network	0-19	20-29	30-39	40-49	50-59	60-69	70-79	≥80	Unknown	Total
1	53	230	641	1,160	1,777	2,208	2,780	1,445	13	10,307
2	163	553	1,524	2,855	4,303	4,869	4,586	2,305	0	21,158
3	79	338	872	1,736	2,614	3,121	2,913	1,515	0	13,188
4	93	334	840	1,671	2,406	3,049	3,461	1,608	0	13,462
5	131	458	1,392	2,538	3,566	3,980	3,847	1,540	0	17,452
6	169	916	2,280	4,174	6,021	6,334	4,935	1,766	0	26,595
7	121	456	1,125	2,168	3,147	3,664	3,948	1,965	1	16,595
8	97	544	1,426	2,661	3,635	3,840	3,233	1,209	0	16,645
9	154	575	1,402	2,676	3,820	4,602	4,805	2,001	1	20,036
10	100	380	870	1,714	2,464	2,794	2,699	1,405	0	12,426
11	114	500	1,265	2,286	3,320	3,622	4,401	2,104	0	17,612
12	102	325	771	1,479	2,014	2,412	2,733	1,355	0	11,191
13	86	435	980	1,934	2,652	2,885	2,327	926	0	12,225
14	201	790	1,918	3,558	5,384	5,632	4,572	1,619	0	23,674
15	124	391	864	1,639	2,564	2,927	2,695	1,059	0	12,263
16	73	268	567	1,023	1,485	1,575	1,626	782	0	7,399
17	92	457	1,074	2,049	3,011	3,380	3,291	1,421	0	14,775
18	215	784	1,616	3,044	4,359	5,040	4,710	2,034	0	21,802
Total	**2,167**	**8,734**	**21,427**	**40,365**	**58,542**	**65,934**	**63,562**	**28,059**	**15**	**288,805**
%Total	**0.8%**	**3.0%**	**7.4%**	**14.0%**	**20.3%**	**22.8%**	**22.0%**	**9.7%**	**0.0%**	**100.0%**

Source: Networks 1-18 Annual Reports, 2001

RACE

While the vast majority of ESRD patients are White, the number of Blacks and Native Americans with ESRD is disproportionately high compared to the U.S. population. While Black Americans comprise 13% of the national population they make up 37.3% of the total ESRD population. Network 6 has a large population of Black patients and Network 15 is home to a large number of Native American patients. Network 16 has a higher population of White patients, 78% compared to the average of 54%. Appendices C and D present tables comparing the dialysis prevalence and ESRD incident populations by race and Network.

DIAGNOSIS

The leading cause of renal failure in the United States is diabetes. A list of primary causes for ESRD can be found in Appendix E. Table 3 and Figure 1 categorize prevalent dialysis patients by primary diagnosis.

Table 3

PREVALENCE OF DIALYSIS POPULATION
BY PRIMARY DIAGNOSIS AND NETWORK WHERE TREATED
December 31, 2001

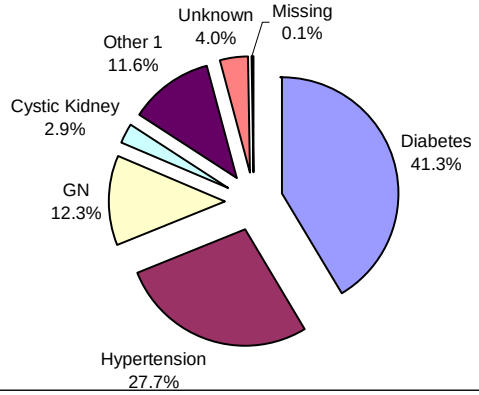
Network	Diabetes	Hypertension	GN	Cystic Kidney	Other [1]	Unknown	Missing	Total
1	3,896	2,359	1,431	414	1,581	546	80	10,307
2	7,934	4,848	2,962	538	3,184	1,692	0	21,158
3	5,340	3,334	2,061	433	1,472	371	177	13,188
4	5,246	3,573	1,823	463	1,796	561	0	13,462
5	6,731	5,796	1,937	465	1,944	536	43	17,452
6	10,347	8,574	3,316	556	2,818	984	0	26,595
7	6,265	5,315	1,933	563	2,025	475	19	16,595
8	6,523	5,707	1,817	462	1,587	518	31	16,645
9	8,422	5,298	2,347	590	2,349	963	67	20,036
10	4,583	4,203	1,337	278	1,423	591	11	12,426
11	7,141	4,863	2,196	565	2,263	584	0	17,612
12	4,523	2,948	1,404	369	1,527	420	0	11,191
13	5,051	4,129	1,233	347	1,135	330	0	12,225
14	11,616	5,956	2,364	566	2,275	897	0	23,674
15	6,337	2,085	1,596	383	1,412	450	0	12,263
16	3,039	1,287	1,128	366	1,206	373	0	7,399
17	6,618	3417	2,191	462	1,577	510	0	14,775
18	9,694	6,189	2,498	584	2,017	820	0	21,802
Total	**119,306**	**79,881**	**35,574**	**8,404**	**33,591**	**11,621**	**428**	**288,805**
%	**41.3%**	**27.7%**	**12.3%**	**2.9%**	**11.6%**	**4.0%**	**0.1%**	**100.0%**

Source: Networks 1-18 Annual Reports, 2001

[1] Other includes data listed as "Other" and "Other Urologic" on Network Annual Reports

Given the diverse patient populations seen within each geographic region it is surprising that there is little variation between the Network populations with respect to the diagnosis of their prevalent populations. All Networks reported diabetes as the primary cause of renal failure in 2001 but Network 15, at 52%, had the highest percentage of patients with this primary diagnosis. Network 6 had a higher percentage of patients with hypertension, 32%.

Figure 1
Prevalent Dialysis Patients by Primary Diagnosis December 2001



Source: Networks 1-18 Annual Reports, 2001

As shown by Figure 1, diabetes represented 41.3% of the prevalent dialysis patient population in 2001. Hypertension followed with 27.7%, glomerulnephritis with 12.3%, and other causes accounted for 11.6% of the dialysis population. Four percent (4%) of patients had an unknown primary cause. Cystic Kidney accounted for 2.9% of the dialysis population. The percentage of patients with a primary diagnosis of diabetes has increased from 41% in 2000 to 41.3% in 2001. Appendix F illustrates the incidence by primary diagnosis by Network. Diabetes is the most common cause of ESRD. The prominent cause of ESRD in women is diabetes, while hypertension is the most common cause of ESRD in men.

GENDER

In 2001, males represented over half (53.7%) of the ESRD incident and dialysis prevalent population. With the exception of Networks 13, all Networks reported a higher ratio of males to females (Appendices G and H).

TREATMENT MODALITY

Today, ESRD patients have a variety of choices for outpatient renal replacement therapy. They have the option of dialyzing at home, in a hospital-based facility, or at an independent facility offering treatment. Some transplant centers, in addition to providing kidney transplants, offer dialysis services. Appendices I and J display the number of dialysis patients in each Network by modality.

While in-center hemodialysis is the predominate modality choice, changes are occurring in peritoneal dialysis (Appendix K). The number of patients undergoing continuous cycling peritoneal dialysis in a self-care setting rose 6% between 2000 and 2001 (Appendix L), however the number of continuous ambulatory peritoneal dialysis patients has decreased by 7%.

Table 4

ESRD PROVIDERS BY TYPE OF SERVICE AND NETWORK

December 2001

Network	Total	Transplant	Dialysis	Hospital [1]	Independent [1]	Inpatient Care	Stations
Total	**4,172**	**240**	**4,024**	**681**	**3,343**	**34**	**67,479**
1	142	15	138	37	101	0	2,279
2	223	15	222	113	109	0	3,700
3	132	6	130	48	82	1	2,318
4	248	15	227	36	191	18	3,841
5	396	13	267	39	228	1	4,129
6	257	10	390	25	365	3	7,610
7	276	10	254	14	240	2	4,424
8	280	12	268	8	260	0	4,769
9	293	15	287	48	239	1	4,529
10	147	8	143	27	116	0	2,254
11	301	20	289	100	189	1	4,085
12	221	19	210	45	165	3	2,834
13	246	14	241	23	218	0	3,740
14	306	23	288	21	267	2	5,712
15	205	13	194	28	166	2	2,838
16	113	7	107	22	85	0	1,619
17	154	8	149	32	117	0	2,530
18	232	17	220	15	205	0	4,268

Source: National Listing of Medicare Providers Furnishing Kidney Dialysis and Transplant Services

[1] Hospital and Independent counts are included in the total dialysis count

Note: Detail does not add to total because most transplant centers also provide dialysis services and are counted again as dialysis providers

Table 4 lists Medicare ESRD providers by type of service offered by Network. There were 240 transplant centers within the United States in 2001. Network 14 has the largest number of transplant facilities, with 23, followed by Network 11, with 20. Network 3 has the fewest transplant facilities, with 6. As expected based on patient populations, Network 6 has the largest number of dialysis providers (390) and Network 16 has the smallest number of providers (107).

Appendix M lists the number of renal transplant recipients by donor source and by Network. According to the annual facility surveys conducted by the Networks, 14,011 transplants were performed within the United States during 2001. Of these transplants, 8,555 were from cadaveric donors while 4,103 were from living related donors and 1,353 from living non-related donors. Cadaveric donors represent 61% of transplants performed. Due to decreases in the availability of cadaveric donors, the percent of living and living unrelated donor transplants have increased in recent years and in 2001 represented 39% of all transplants performed. A large number of patients are on waiting lists for kidney transplants. According to the United Network for Organ Sharing (UNOS), there are currently 53,259 potential kidney recipients on the Organ Procurement and Transplantation Network (OPTN) national patient waiting list.

The transplant centers in Network 11 performed the largest number of transplants in 2001. Network 11 also had the largest number of transplants by living related donor, 591, and 241 transplants by a living

unrelated donor. Network 3 had the fewest number of transplants with 357 occurring. Network 3 also had the least number of transplants by living related donor, 82.

NETWORK DESCRIPTION

The ESRD Network program began in 1977 when the Department of Health and Human Services (formerly Department of Health, Education and Welfare) published the final regulations establishing 32 Network Coordinating Councils to administer the newly funded program. With only 40,000 dialysis patients receiving care in 600 facilities, the Networks' responsibilities focused on organizational activities, health planning tasks, and medical review activities.

By December 31, 1987, the ESRD program encompassed 98,432 patients and 1,701 facilities administering renal replacement therapy. At this time, Congress consolidated the 32 Networks into 18, redistributing and increasing their geographical areas as well as their program responsibilities. Funding mechanisms changed when Congress mandated that $ 0.50 from the composite rate payment from each dialysis treatment be withheld and allocated to fund the ESRD Network program. In 1988 CMS began formal contracting with the ESRD Networks to meet their legislative responsibilities. These contracts placed greater emphasis on quality improvement activities and standardizing approaches to quality assessment. Networks still collected and analyzed data for quality improvement, but health-planning functions were reduced.

In 2001, the ESRD program encompassed 288,805 patients and 4,172 facilities. The Networks now operate on a three-year Statement of Work (SOW) cycle. The 2000 - 2003 SOW was implemented in July 2000. At the time of the contract renewal, CMS provided an updated ESRD Network Organization Manual that provided background and articulated responsibilities of the Networks as well as modifications to some requirements of the ESRD Network program. This tool enables the Networks to better understand contract responsibilities.

As specified in the Statement of Work, each Network is responsible for conducting activities in the following areas:

1. Quality Improvement
2. Community Information and Resource
3. Administration
4. Information Management

CMS contracts require each Network to have an Executive Director, a Director of Quality Improvement, and a Director of Data Management as well as other necessary staff to fulfill the contract obligations. The role of the Executive Director is to coordinate the activities of the Network. The Director of Quality Improvement coordinates quality-related requirements and creates and implements quality improvement projects. The role of the Director of Data Management is the accurate recording and transmission of data between the facilities, the Network, and CMS.

In addition to these staff members, Networks employ other individuals to accomplish contract responsibilities. Though these positions vary from Network to Network, additional staff in the areas of quality improvement, data, and patient services are essential for the coordination of the many Network activities. Table 5 shows the type, number, and percent of staff employed by each Network.

Table 5
NETWORK STAFF BY TYPE, NUMBER, AND PERCENT
December 31, 2001

Network	ESRD Providers*	Administrative #	Administrative %	Quality #	Quality %	Data #	Data %	Patient Services #	Patient Services %	Total Staff
1	142	3	30%	2	20%	4	40%	1	10%	**10**
2	223	3	25%	2	17%	5	42%	2	17%	**12**
3	132	1	13%	3	38%	3.5	44%	0.5	6%	**8**
4	248	3	27%	3	27%	4	36%	1	9%	**11**
5	396	4	36%	4	36%	2	18%	1	9%	**11**
6	257	3	25%	3	25%	5	42%	1	8%	**12**
7	276	2	25%	2	25%	2	25%	2	25%	**8**
8	280	2	20%	2.5	25%	4.5	45%	1	10%	**10**
9/10	440	4	25%	4	25%	5	31%	3	19%	**16**
11	301	2	17%	3	25%	6	50%	1	8%	**12**
12	221	3	38%	1	13%	3	38%	1	13%	**8**
13	246	2.25	20%	4	36%	3.25	30%	1.5	14%	**11**
14	306	2	18%	3.5	32%	4	36%	1.5	14%	**11**
15	205	4	36%	2	18%	4	36%	1	9%	**11**
16	113	2.5	34%	1	14%	3	41%	0.8	11%	**7.3**
17	154	2	24%	2.6	31%	3.2	38%	0.6	7%	**8.4**
18	232	3	33%	3	33%	3	33%	0	0%	**9**
TOTAL	**4,172**	**45.75**	**26%**	**45.6**	**26%**	**64.45**	**37%**	**19.9**	**11%**	**175.7**

Source: Networks 1-18 Annual Reports, 2001

*Source: National Listing of Medicare Providers Furnishing Kidney Dialysis and Transplant Services

As seen in Table 5, Networks operate with a relatively small number of employees for the size of the ESRD patient population served. The staffing pattern is similar across the Networks, with respect to the number of staff assigned to functional categories, but still reflect regional variations. The staff classification areas above are for calculation purposes only and often do not indicate the true full-time equivalency of staff work duties. For example, an administrative assistant may be responsible for supporting the quality improvement staff a portion of the time and the data staff the rest of the time.

Network staff are supported by a variety of committees with volunteer members from within the Network area. Each Network is required by contract to specify appropriate roles and functions for these committees. Each Network is required to have the following:

- **Network Council:** A body composed of renal providers in the Network area that is representative of the geography and the types of providers/facilities in the entire Network area. The Council also includes at least one patient representative. The Network Council serves as a liaison between the provider membership and the Network.

- **Board of Directors (BOD):** A body composed of representatives from the Network area, including at least one patient representative. The BOD (or Executive Committee) supervises the performance of

the Network's administrative staff in meeting contract deliverables and requirements and maintains the financial viability of the Network.

- **Medical Review Board (MRB):** A body composed of at least one patient representative and representatives of each of the professional disciplines (physician, registered nurse, social worker, and dietitian) that is engaged in treatment related to ESRD and qualified to evaluate the quality and appropriateness of care delivered to ESRD patients.

- **Any other committees** necessary to satisfy requirements of the SOW. These committees are designated by the Network and/or BOD and may include, but are not limited, to patient advisory, grievance, organ procurement, transplant, finance, and rehabilitation.

CMS NATIONAL GOALS AND NETWORK ACTIVITIES

The current Statement of Work outlines four goals to provide direction to the national ESRD Network program. These goals outline the basic functions of the ESRD Networks and are used to direct the Network daily activities. Each Network tailors its activities to meet and exceed CMS expectations.

The four goals are:

1. Improving the quality of health care services and quality of life for ESRD beneficiaries;
2. Improving data reporting, reliability, and validity between ESRD facilities/providers, Networks and CMS;
3. Establishing and improving partnerships and cooperative activities among and between the ESRD Networks, Quality Improvement Organizations, State Survey Agencies, and ESRD facilities and providers; and,
4. Evaluating and resolving grievances.

These goals and how the Networks accomplished them are discussed below.

GOAL ONE: IMPROVING THE QUALITY OF HEALTH CARE SERVICES AND QUALITY OF LIFE FOR ESRD BENEFICIARIES

The Centers for Medicare & Medicaid Services (CMS) contract with the 18 ESRD Networks to design and administer quality improvement/assessment programs. The structure and composition of the Networks place them in a unique position to accomplish this purpose. The Networks are not-for-profit organizations, led by volunteer boards and committees comprised of nephrology patients and professionals. CMS outlines the broad expectations for Networks and specifies projects and tasks in the ESRD Network Statement of Work (SOW). The geographic distribution of the 18 Networks allows each to design projects most appropriate for the population served. The Networks can adapt projects for the different cultural and clinical needs of the area and take advantage of local resources to advance the project. With limited resources, Networks must determine which projects can have the broadest impact on improving quality of care. Networks share these project ideas with one another so successful projects can be duplicated.

The Networks serve as liaisons between CMS and ESRD providers, and also between providers and the ESRD patients under their care. CMS, providers, and patients all have a vested interest in achieving optimal treatment, and the Networks serve as a vital link in the quality chain. Network organizations accomplish their quality mission by:

1. Collecting and validating data;
2. Distributing data feedback reports for facilities to use in improving care;
3. Conducting quality improvement projects and activities focused on specific areas of care;
4. Providing professional educational materials and workshops for facility staff;
5. Providing patient educational materials and workshops to facilities and directly to patients; and
6. Offering technical assistance to dialysis and transplant facilities.

COLLECT AND VALIDATE DATA

ESRD Networks routinely collect, validate, and report patient-specific and facility-specific data for many uses. Data collected by the Networks are used to provide CMS and other agencies with data for operational activities and policy decisions. Networks also supply data and/or support to the USRDS and to other research organizations. Data collected by the Networks are used to report on renal trends to the renal community and beyond. Examples of data collected by the Networks are listed in Table 6 below.

Table 6
DATA COLLECTED
BY NETWORKS AS REQUIRED BY CONTRACT

Standard CMS Forms	CMS - 2728: Medical Evidence CMS - 2746: Death Notification CMS - 2744: Annual Facility Survey	Demographics and pre-ESRD clinical data for all new ESRD patients Date and cause of death Reconciliation of patient activity
Minimum Data Set (No Standard Forms)	Non-clinical Patient Events Facility Characteristics and Staff	Allows Networks to place patient on any given day by treatment center and type of modality Size, ownership, staffing
Standard CMS Clinical Performance Measures	CMS - 820: Hemodialysis CPM Form CMS - 821: Peritoneal Dialysis CPM Form No number: Facility CPM Form	Clinical performance forms collected once per year on a sample of patients in each Network
Infectious Disease	Centers for Disease Control (CDC) National Surveillance of Dialysis Associated Diseases	Facility-specific outcomes and practices

ESRD Networks also use data in their individual quality improvement projects. Data collected for quality improvement projects are protected from release to the public.

National Clinical Performance Measures (CPM) Project

This project, formerly known as the National ESRD Core Indicators Project, involves the collection and reporting of these data provides the foundation for many of the Network quality improvement activities. It provides important feedback on outcome measures at both the national and Network levels. The four areas of care identified by CMS for the focus of this project are listed below:

- Adequacy of dialysis measured by
  - URR and Kt/V (hemodialysis)
  - Weekly Kt/V and Creatinine Clearance (peritoneal dialysis)
- Nutritional status measured by
  - Albumin

- Anemia management measured by
    - Hemoglobin
- Vascular access
    - Hemodialysis only

Each year, CMS (or its contractor) draws a 4% sample of adult hemodialysis patients and a 5% sample of adult peritoneal dialysis patients. Networks prepare and distribute the collection forms. Facility personnel collect data from the fourth quarter of the previous calendar year for the hemodialysis cohort. Data for the peritoneal cohort is from the fourth quarter of the previous calendar year and the first quarter of the current year. Data from all in-center hemodialysis patients from ages 0-18 (n = 869) were also included in the CPM sample. In 2001 Networks processed CPM forms on 8,863 hemodialysis patients and 1,451 peritoneal dialysis patients.

When completed forms are submitted, Networks review the forms, input the data using standard software supplied by CMS, and transmit the data to the CMS contractor. CMS and/or its contractor then randomly selects 5% of the original patient sample (hemodialysis and peritoneal dialysis) for validation. Networks re-abstract data for cases in the validation sample (either on-site or via mailed medical record copies), computerize the information, and transmit it to the CMS contractor.

This Project provides national and Network-specific rates based on the clinical performance measures employed in the four areas of care. CMS uses these data to assess the quality of care being delivered to Medicare beneficiaries and to evaluate the effectiveness of the Network program in improving care. Networks use the Report, in combination with other feedback reports, to select areas for quality improvement/assessment projects and activities. Since the sample size is insufficient to provide facility-specific reporting, many Networks collect data on a broader sample in order to produce facility-specific rates on outcome measures. Methods used for this include:

- 100% of patients from 100% of facilities;
- Sample of patients from 100% of facilities; and
- Aggregate facility data from 100% of facilities.

Selected findings from the 2002 ESRD Clinical Performance Measures Project are highlighted below. Important improvements in adequate therapy and anemia management have been realized since the onset of this project. It is important to note that although the project year is 2002, the data are from 2001. When years are noted in the information below, it refers to the year the data were collected, not the project year.

Adequacy of Dialysis: Hemodialysis

- Mean URRs have increased each year that the project has been conducted, from 62.7% in 1993 to 71.5% in 2001.
- The proportion of patients with mean URRs ≥ 65 has also increased steadily from 43% in 1993 to 84% in 2001.
- 89% of patients had a mean delivered Kt/V ≥ 1.2 in 2001, representing a 15% increase from 74% in 1996 when Kt/V was introduced in the project.
- The mean Kt/V was 1.49.

Adequacy of Dialysis: Peritoneal Dialysis

- Adequacy of dialysis was assessed during the study period (October 2001-March 2002) for an estimated 86% of patients. This is a dramatic increase from 66% in 1995 when a peritoneal dialysis cohort was first added to the project.
- 68% of CAPD patients had both a mean weekly Kt/V ≥ 2.0 and creatinine clearance ≥ 60 L/wk/1.73m2 or there was evidence that dialysis prescription was changed if the adequacy measurements were below these thresholds during the six-month study period.
- 61% of cycler patients (no daytime dwell) had a mean Kt/V ≥ 2.2 and a mean weekly creatinine clearance of ≥ 66 L/wk/1.73m^2.
- 70% of cycler patients (with daytime dwell) had a mean Kt/V ≥ 2.1 and a mean weekly creatinine clearance of ≥ 63 L/wk/1.73m^2.

Vascular Access: Hemodialysis

- 29% of incident patients were dialyzed using an AV fistula.
- 31% of prevalent patients were dialyzed using an AV fistula.
- 19% of prevalent patients were dialyzed with a chronic catheter continuously for 90 days or longer.
- 51% of prevalent patients with an AV graft were routinely monitored for the presence of stenosis.

Anemia Management: Hemodialysis

- In 2001, the proportion of patients with a hemoglobin ≥ 11 was 76%, compared to 68% in 1999.
- The mean hemoglobin increased from 11.4 gm/dL in 1999 to 11.7gm/dL in 2001.

Anemia Management: Peritoneal Dialysis

- The mean hemoglobin in 2001-2002 was 11.8 gm/dL.
- 76% of patients had a mean hemoglobin of ≥ 11 gm/dL, compared to 68% in the 1998-2000 study period.

Serum Albumin: Hemodialysis

- The percent of patients with *adequate* mean serum albumin values ≥ 3.2 (BCP) or 3.5 (BCG) in 1999 was 82%, compared to 77% in 1993.
- The percent of patients with *optimal* mean serum albumin values ≥ 3.7 (BCP) or 4.0 (BCG) in 1999 was 36%, compared to 27% in 1993.
- Mean serum albumin value in 2001 with bromcresol green (BCG) laboratory method was 3.8 gm/dL, unchanged from 1999.
- Mean serum albumin value in 1999 with bromcresol purple (BCP) laboratory method was 3.6 gm/dL, compared to 3.5 gm/dL in 1999.

Serum Albumin: Peritoneal Dialysis

- The mean serum albumin value for 1999 was 3.6 gm/dL (BCG) and 3.3 gm/dL (BCP), slightly increased changed from 1999.
- The percent of patients with *adequate* mean serum albumin ≥ 3.2 (BCP) and 3.5 (BCG) was 61%.
- The percent of patients with *optimal* mean serum albumin values ≥ 3.7 (BCP) or 4.0 (BCG) was 19%.

DISTRIBUTE DATA FEEDBACK REPORTS FOR FACILITY USE IN IMPROVING CARE

Feedback reports and facility-specific data have become a major aspect of Network quality activities. During 2001, all Networks distributed the data feedback reports, listed below, to their constituent dialysis and transplant facilities. In addition to these "standard or routine" reports, most Networks generate and distribute other reports (many are facility-specific) as a product of their quality assessment and improvement activities. These additional reports are referenced in the section describing Other Quality Activities (Appendix N).

- Annual Report of Network activities and accomplishments
- Annual Report of the ESRD Clinical Performance Measures Project, and subsequent Supplemental Reports
- Unit-specific reports of standardized mortality, morbidity, and other rates, produced by the University of Michigan Kidney Epidemiology and Cost Center
- Summary of the Center for Disease Control and Prevention National Surveillance of Dialysis Associated Diseases
- Forms compliance reports

CONDUCT QUALITY IMPROVEMENT PROJECTS (QIPs) AND ACTIVITIES FOCUSED ON SPECIFIC AREAS OF CARE

Quality Improvement Projects

The ESRD Network contract with CMS requires implementation of two Quality Improvement Projects (QIPs) per contract cycle. These are in-depth projects for which CMS prescribes the format. The Projects must address an area of care for which clinical performance measures and indicators have been developed, and the proposal must be submitted to CMS for approval prior to implementation.

The QIP format requires that each Network clearly define the opportunity for improvement, employ both outcome and process indicators, include a project design and methodology that supports statistical analysis, propose intervention activities, and include an evaluation mechanism. For 2001, CMS requested all Networks conduct a QIP on Vascular Access. Three projects were proposed for these studies:

- Increasing AV Fistulas – This project addresses one of three vascular access measures in the ESRD Clinical Performance Measures Project: Vascular Access CPM I, Maximizing Placement of Arterial Venous Fistulae (AVF). This measure follows Guideline 29 of the National Kidney Foundation's Dialysis Outcomes Quality Initiative (NKF-DOQI) 2001 Update.
- Vascular Access Monitoring – This measure addresses Vascular Access CPM IV: Monitoring Arterial Venous Grafts for Stenosis and follows Guideline 10 of the K/DOQI as contained in the July 21, 2000, Medicare ESRD Network Organizations Manual: Monitoring Dialysis AV Grafts for Stenosis.
- Reduction of Catheters in Hemodialysis – This project intends to lower the Network Catheter rate to the K/DOQI guideline of 10% per facility. The project address the assessment of patients who had catheters as the primary vascular access for more than 90 days, the employment of appropriate clinical processes to ensure appropriate and timely referral for an access (graft or fistula), and a concomitant reduction of catheters in hemodialysis (HD) patients.

A brief overview and status of the Network projects addressing vascular access is displayed in the table below.

Table 7
2001 QUALITY IMPROVEMENT PROJECTS

QIP's Addressing Vascular Access		
Network	**Goal**	**Status at December 2001**
Reduction of Catheters		
1	To identify all catheter patients as of May 2002 in all providers that exceed 10% of their patient census that have catheters> 90 days.	Will identify the subset of patients that inappropriately have a catheter. Will assist providers in evaluating their internal process methods and foster referral to surgeons for assessment of other access options.
2	Assessment and Reduction of Catheters in Hemodialysis	Project will be initiated in 2002.
3	To lower the number of patients with catheters in place for more than 90 days. Facilities will have a process for the patient vascular access plan.	Data collection tool was developed including facility-specific questions and patient-related questions. 26 facilities (20 in New Jersey, 6 in Puerto Rico). To be implemented in 2002.
5	The major focus of the project is to reduce the number of patients inappropriately dialyzing via catheter > 90 days. The improvement goal is to reduce the number of patients dialyzing by catheter > 90 days by 50%.	The Narrative Project Plan (NPP) for this project was submitted for approval in November 2001. (Final approval was received in 2002.)
6	To lower facility catheter rates in Network 6 towards the NKF-K/DOQI recommendation of less than 10%.	The Narrative Project Plan had been submitted to CMS.
7	For all outpatient hemodialysis facilities to identify and reduce the number of catheters in place > 90 days in a patient who is eligible for a long-term vascular access. Goal to lower rate to NKF-K/DOQI guideline of 10% patients with catheters per facility.	Project approved 4th quarter of 2001. Network staff began development of the Narrative Project Plan based on the catheter project template designed by a national committee.
9/10	To target vascular access management, the increasing Network 9/10 catheter rates, and analysis of reasons for catheter.	The Narrative Project Plan was submitted to CMS in December. The project proposes a start date of April 2002.
11	To (a) improve the process by which patients are referred for permanent access placement during the first 6 months of hemodialysis, and (b) overcome barriers to timely placement of permanent access.	This QIP will target all adult, in-center patients starting hemodialysis (incident patients) from January 1, 2002, through June 30, 2002. The results of the QIP will be compared with the previous Network vascular access data collections from 1999 and 2001.
12	Reduction of Catheters - to improve the process by which patients are referred for permanent access placement during the first 6 months of hemodialysis and to overcome barriers to timely placement of permanent access.	This QIP will target all adult, in-center patients starting hemodialysis (incident patients) from January 1, 2002, through June 30, 2002.

QIP's Addressing Vascular Access		
Network	**Goal**	**Status at December 2001**
13	All outpatient hemodialysis units will have a written process by which vascular access is assessed and documented and catheters are identified for further intervention.	The Narrative Project Plan (NPP) was submitted to the CMS Dallas Regional Office on November 30, 2001. Work towards its eventual implementation remains ongoing in 2002, pending final regional office approval of NPP.
15	Achieving a URR of ≥ 65% in all hemodialysis patients (including those with catheters). Secondary goal: to have less than 10% of chronic maintenance hemodialysis patients maintained on catheters as their permanent chronic dialysis access.	The Project Idea Document (PID) was submitted on September 22, 2000, approved on September 25, 2000; the final NPP was approved on March 14, 2001. A post-intervention follow-up data collection will be completed (February 2002).
Stenosis Monitoring		
4	Increase the implementation of routine monitoring programs within Network 4 as recommended in the NKF-K/DOQI Guidelines for stenosis of arterial venous grafts in the chronic outpatient dialysis facilities.	The CMS Boston Regional Office accepted the proposal on October 2, 2001, and the Narrative Project Plan was submitted on November 30, 2001. The project will be implemented in 2002 after receiving final Regional Office approval.
8	To increase the number of facilities performing routine vascular access monitoring by one of the K/DOQI recommended methods and guidelines.	Received approval on PID and initial NPP. Plans being confirmed for intervention workshops with facilities identified which perform no monitoring.
12	Focus on increasing implementation of the Kidney Dialysis Quality Outcomes Initiative (K/DOQI) clinical practice guidelines. Work with 30 facilities that either do not have policies or do not perform the recommended stenosis monitoring procedures to increase guideline usage.	Awaiting approval from CMS, initiation date of February 2002.
14	Increase vascular access stenosis monitoring and surveillance processes in dialysis facilities. Encourage the practice of reporting and proactively responding to vascular access thrombosis data in facility QM programs. Minimizing incidence of clotted grafts by referring patients to a specialist for diagnostic testing when indicators of possible stenosis are identified.	Baseline collection data collected. Benchmark facility practices documented, project report and MRB recommendation distributed. Regional educational seminars produced. Follow-up data collection pending.
17	Three goals have been identified: (1) 100% of hemodialysis facilities will have a methodology to track graft failure rates via a "Graft Thrombosis Rate"; (2) 100% of hemodialysis facilities will monitor for indicators of stenosis in A-V grafts; and (3) 100% of all A-V graft patients with indicators for stenosis in a selected sample of Network 17 hemodialysis facilities will be referred and receive corrective treatment.	Awaiting approval from CMS. Initiation date anticipated May 2002.
18	To decrease the incidence of clotted AV grafts, to increase monitoring of AV grafts, to promote formal access management programs in all hemodialysis facilities, and to prevent the loss of the vascular access by assuring early referral for diagnostic evaluation and treatment when stenosis indicators are found.	Study will officially begin in 2002.

QIP's Addressing Vascular Access		
Network	**Goal**	**Status at December 2001**
AV Fistula		
15	The Arterio Venous Fistulas rate in Network 15 by CPM measurement in 2000 was 33% and as measured in the current Adequacy/Access QIP, 36.6%. Variation among the six states comprising Network 15 from 24.5-46.0% indicates an opportunity to increase fistula rates within Network 15.	The PID was submitted to the CMS Project Officer on October 8, 2001, and approved on October 18, 2001. The NPP was submitted on December 14, 2001, and had not yet received final approval by the end of the calendar year.
16	Increasing the Use of Arterio Venous Fistulas. Facilities with less than 40% of HD patients utilizing AVFs were targeted for intervention; experts were identified and asked to share their best and effective practices with members of the renal community.	Four regional workshops, targeted to nephrologists, vascular access surgeons, interventional radiologists, and vascular access managers affiliated with the intervention facilities, will be conducted in Spring 2002.

Source: Networks 1-18 Annual Reports, 2001

In addition to vascular access, Networks addressed other areas of care through the conduct of Quality Improvement Projects during 2001. The table below provides an overview of the approved QIPs by area of care.

Table 8
QIP'S BY AREA OF CARE

Network	Goals	Status at December 2001
Adequacy of Peritoneal Dialysis		
2	Improving Peritoneal Dialysis Adequacy measures: To increase the percent of patients whose adequacy measures meet or exceed the DOQI Guidelines for Creatinine Clearance (Ccr) and/or Kt/V.	Both indicators of quality showed improvement in the intervention group: 21.7% Ccr and 15.7% Kt/V.
5	1. Increase the proportion of PD patients with adequacy measured (method and frequency) in accordance with K/DOQI Guidelines. 2. Increase the proportion of patients receiving adequate PD as defined by K/DOQI Guidelines.	Re-measurement data were collected from the time period January-June 2001, and this was completed in December 2001.
Adequacy of Hemodialysis		
1	Have 80% of all hemodialysis patients receive an adequate dialysis, as measured by their urea reduction ratio (URR).	Only 5% of providers remained below the 80% URR benchmark. MRB physician consultation with Medical Directors to explore barriers. Post intervention measurements Spring of 2002.
2	Empowering Nurses to Improve Hemodialysis Adequacy: To increase the percent of patients with URR > 65% in selected facilities through the initiation of a nurse-managed hemodialysis adequacy protocol.	Data collection was completed in March 2002. Reports will be distributed to providers in the fall of 2002.

Network	Goals	Status at December 2001
3	Hemodialysis Adequacy Prescription Quality Improvement Project (HAPQIP). Network 3 met the benchmark of at least 80% of hemodialysis population with URR of 65%. For further improvement, returned to the beginning of the process that is hemodialysis prescription. Goal to increase the number and percentage of patients who receive adequate dialysis.	Initiated in 2001, innovative use of technology (use of electronic format, Website with instant feedback for some components). Some technical difficulties experienced. Analysis of project to be completed in 2002.
4	Adequacy of Hemodialysis QIP (2000-2001): Increase proportion of patients with a catheter as the primary access to URR ≥ 65% through subsequent reduction in catheter malfunction.	Remeasurement data has been entered and analysis has begun.
7	To improve the adequacy of in-center hemodialysis among adult patients receiving dialysis, as evidenced by a urea reduction ratio of > 65% during July, August, and September 2000. At least 80% of Network hemodialysis patients will have a URR > 65%. Identify intervention strategies within a sample group.	Final analysis of project with the epidemiological consultant.
8	To increase the % of patients with URR greater than 65%, which was the CPM measure. The project design was a two-phase pre-test/post-test with identical interventions delivered to the target (phase I) group and later to the comparison (phase II) group. Network intervention activities were focused workshops for physicians and nurses. Data for this project were collected in three time periods: December 2000 (baseline data), March 2001 (Phase I: Post-Intervention Follow-up) and June 2001 (Phase II: Post-Intervention Follow-up). Educational workshops were held in January 2001 for the phase I group and in late March 2001 for the phase II group. Data analysis took place in June and July 2001.	The data analysis suggested that the interventions were successful among target populations. Mean URR scores among patients with a URR < 65% in December 2000 increased significantly (.01) in March and were maintained in May re-measurement in both the Phase 1 and Phase II groups. An unexpected outcome of this project was among those patients who had an initial URR ≥ 65%, which had a significant decrease (.01) in the number of patients with a URR ≥ 65% in both March and May.
9	Primary objective: 85% of adult, in-center HD patients to meet or exceed the URR target of ≥ 65%. Secondary objective: measure and improve components of adequacy. Third objective: evaluate the facility interventions and the effect on URR.	Project concluded December 2001; final report is pending CMS approval. Network goal of ≥ 85% of facilities with a URR ≥ 65% was achieved with a mean URR ≥ 65% of 85.2 in non-intervention facilities. Intervention facilities fell slightly short with a mean URR ≥ 65% of 84%.
10	Primary objective: 80% of adult, in-center HD patients to meet or exceed the URR target of ≥ 65%. Secondary objective: measure and improve components of adequacy. Third objective: evaluate the facility interventions and the effect on URR.	Project concluded December 2001; final report is pending CMS approval. Network goal of ≥ 80% of facilities with a URR ≥ 65% was achieved with a mean URR ≥ 65% of 83.4 in the non-intervention facilities but not achieved in intervention facilities with a mean URR ≥ 65% of 77.9.
11	Facilities were selected for inclusion based on 4th quarter 1999 Elab results. Those facilities with < 80% of patients with URR ≥ 65% were included in the intervention group.	39 facilities attended one of four regional workshops. Improvement was measured based on data collected for the 3rd quarter of 2001. Patients with URR ≥ 65%, rose to 76.5 % from 62.6%. 4th quarter data showed 83.3% patients with URR ≥ 65%.

Network	Goals	Status at December 2001
12	To improve the effectiveness of hemodialysis treatments received by in-center patients: URR with a 65% value being the threshold for appropriate care.	Unit's improvement goals were communicated on the monthly URR run chart. Facilities experiencing difficulty achieving either the 80% threshold or the 10% improvement goal received educational materials on improving hemodialysis adequacy.
13	To increase the percent of hemodialysis patients for whom vascular access is a catheter who receive adequate hemodialysis therapy (URR greater than 65%) from less than 60% to at least 80% by December 2001.	Baseline data collection and intervention accomplished. Initial Narrative Project Plan (NPP) was submitted to CMS Regional Office; final approval received on April 10, 2001.
14	Increase the percent of patients attaining the recommended level of hemodialysis adequacy (URR of >65% or Kt/V of > 1.2 dialysis facilities). Identify the unique patient characteristics and causes why patients are unable to attain recommended level of dialysis adequacy for three months or longer. Educate and assist facilities with developing strategies to minimize underdialysis.	Outcome goals met. Increased dialysis dose delivered to patients identified as underdialyzed at baseline. Identified common causes. Project completed, results disseminated to CMS and dialysis community.
15	Achieving a URR of ≥ 65% in all hemodialysis patients (including those with catheters). Secondary goal: to have less than 10% of chronic maintenance hemodialysis patients maintained on catheters as their permanent chronic dialysis access.	The Project Idea Document (PID) was submitted on September 22, 2000, approved on September 25, 2000; the final NPP was approved on March 14, 2001. A post-intervention follow-up data collection will be completed (February 2002).
16	"Improving the Overall Adequacy of Hemodialysis: Verifying the Consistency of Delivered Dose of Dialysis". Network 16 met national goals for proportion of patients receiving adequate dialysis as per CPM measures. However, CPMs are gathered at predictable periods. Additional data from two time periods was analyzed to determine whether patients received adequate dialysis during the treatments when their URRs and/or Kt/Vs are not measured via the CPM study.	Concluded that dialysis is as adequately delivered during “non-index” treatments as during the treatment when URR and/or Kt/V are measured.

Network	Goals	Status at December 2001
17	Initiate facility staff awareness of discrepancies between prescribed and delivered treatment and increase documentation of any change to treatment parameters within two weeks of a URR less than 65%. Thirty-eight intervention facilities were selected.	This project utilized a post-test design and included basic information about dialysis and issues to be considered if a patient did not achieve adequate dialysis. 612 of 900 staff in the 38 intervention facilities completed this task within the 25 day turnaround period. The educational intervention used in this project did not result in an increase in the proportion of patients with a URR less than 65% who had an adjustment to treatment. The one month intervention period was a limiting factor for anticipated behavioral facility staff changes. The project did provide insight to possible reasons for a URR to be below 65% other than inadequate dialysis. These were recovered renal function and use of Kt/V as the more common method of measuring adequacy. The project found that 62% of patients in intervention facilities had RRF. The limitations/ barriers of this project included only a three month period, in which the project was to be initiated, interventions provided, and remeasured.
18	To focus on quality indicators related to adequacy prescription elements. Outcome indicators included the percentage of hemodialysis with a URR > 65% and the percentage of particular types of vascular access in project patients.	Demonstrated increasing time and blood flow rates can provide relative improvement in URR results. Annual clinical indicators will provide continual monitoring of this indicator, all Network 18 facilities will continue to receive specific profiling data annually, and the Medical Review Board will follow up with facilities not meeting Network goals.
Vascular Access		
1	Increasing the Utilization of Permanent Access in Incident Hemodialysis Patients. Phase I - The Pre-ESRD Course to Dialysis and Selection of Primary Access Type. Phase 2 - The Surgeon's Viewpoint on Selection of First Vascular Access Type.	Phase 1: Conclusions: New ESRD patients are common and are less likely to receive a fistula as their initial hemodialysis access. Phase 2: Conclusions: The feasibility of creating a fistula is not equal for all patients. Requires greater educational effort in the preservation of veins and earlier referral of pre-ESRD patients to renal management. Encourage establishment of pre-ESRD clinics.
18	Vascular Access QIP Follow-up: Incident Patient Data. Data collected to determine facility and Network AVF, graft, and catheter rates.	Incident AVF rate (29%) was above the national results of 27% for that time period (CPM 2001), but significantly below the AVF rate recommended by the K/DOQI vascular access clinical guidelines.
Preventative Care		
2	Management of Diabetes for Patients with Chronic Renal Failure: To increase provider awareness of key screening processes that constitute appropriate management of dialysis patients with diabetes.	Demonstrated effectiveness of interventions to increase the proportion of patients monitored for complications of diabetes per ADA recommendations. Observation: not all care is coordinated through the hemodialysis unit and nephrologists are not functioning as gatekeepers of care.

Network	Goals	Status at December 2001
3	Improve Patient Care: To encourage utilization of recent scientific evidence to improve patient care. Anemia management, nutrition, dialysis adequacy, and vascular access activities included.	Anemia management - monthly hemoglobin values were tracked. % of patients with hemoglobin levels of at least 11 gm/dl rose from 73% to 73.7%. 4,901 newly diagnosed in-center patients entered the staff-assisted treatment system. Facilities increased the number of patients and % of caseloads that received a dose of elevated hemodialysis equivalent to at least a URR of 65%.
4	Early Referral to Nephrology Care QIP (1998-1999): Increase PCP awareness of importance of early referral and increase by ten percentage points the placement of vascular access thirty days prior to dialysis.	The final report was accepted and approved by CMS on September 20, 2001. Requests continued to be received from facilities for the video and educational materials.
4	Influenza Immunization QIP (1999-2000): Increase the proportion of ESRD patients who were informed about the medical benefits of immunization. Increase the number of ESRD patients who received an immunization.	Seventy-seven percent of the patients were immunized in 1999-2000 and 80.3% of the Network 4 patients were immunized in the 2000-2001 influenza season. This QIP was concluded March 1, 2001, and the final report was accepted and approved on August 8, 2001.
5	Preventive Care: Increasing The Influenza Vaccination Rate: 1. Increase proportion of Network 5 facilities offering flu shots on-site, or referring patients elsewhere for annual vaccination. 2. Increase proportion of Network 5 patients receiving flu shots annually.	The 2001 CDC Survey data showed that 90.5% of Network 5 facilities offered flu shots on-site. According to Medicare claims data from 2000, 41.4% of Network 5 patients were vaccinated against influenza, compared to 38.2% nationally. Project implemented in 1997 and completed in 1998. Promotional materials distributed annually (in partnership with area QIOs), and annual follow-up conducted.
Transplantation		
3	To promote patient access to kidney transplantation as a treatment choice though active support of patient education, assessment, and organ procurement. Activity: Dialysis facility transplant designees track and report activity changes via TARC web site data entry. Activity: After application for the transplant center's exclusion criteria, 100% of Network-wide caseload will be referred for transplant evaluation within one year of beginning new course of dialysis. Activity: Within 60 days of being contacted, transplant centers will arrange for a transplantation evaluation appointment for 100% of consumers referred to them.	Consumers on dialysis reviewed for preliminary medical suitability according to medical criteria, 2710 patients referred to transplant surgeons for evaluation, an increase of 25% over 2000. 5% increase patients on cadaveric transplant list. ESRD facilities have established relationships with local organ procurement organizations, participated in educational programs, and updated internal policies. Future plans to establish data entry functionality via the TARC website.

5	Transplant Education and Referral: Standardize the presentation of transplant information to all medically eligible dialysis patients at the facility level by conducting workshops to educate staff regarding all aspects of transplant, i.e., eligibility, cost, surgical procedure, donor procedure, and immunosuppression.	Long-term comparison revealed that two intervention facilities showed statistically significant improvement in (1) the percentage of patients waitlisted for transplant of scheduled for living donor transplants and (2) patients referred to a center for medical evaluation to receive transplant. Control facilities showed no statistically significant improvement; mean increase was 18.3% (range –21.0% to 57.3%). Conclusions about expansion to all Network dialysis facilities have not been reached, barriers to patient transplant education appear to exist at the dialysis facility level due to frequent turnover of staff who conduct this education.
11	Monitor first-year outcomes.	First-year outcomes were published in Network Annual Report and MRB reviewed three-year trend data.

Source: Networks 1-18 Annual Reports, 2001

Quality Improvement Activities

In addition to formal Quality Improvement Projects, Network Medical Review Boards (MRB) also conduct quality assessment and improvement activities to address areas of concern and opportunities for improvement. These utilize individualized approaches and may be specific to the Network area. In 2001, Networks conducted numerous quality activities employing various approaches that included distributing data feedback reports, disseminating information using hardcopy or electronic transmission, patient counseling, benchmarking, and knowledge management.

An overview of these activities is described in the table below, by area of care. A more detailed explanation of the activities by Network is included in Appendix N.

Table 9
SUMMARY OF OTHER NETWORK QUALITY ACTIVITIES CONDUCTED IN 2001

Area of Care	Networks
Adequacy of Dialysis (HD and/or PD)	3, 5, 6, 11, 13, 15, 16
Anemia Management	1, 2, 6, 11, 13, 18
Vascular Access	5, 6, 8, 12, 13, 18
Patient Support	8, 17
Patient Safety	8, 12, 15, 17
Modality Selection Study	18
Renal Osteodystrophy	11
Bacteremia and/or Infection Control	1, 8, 13
Vocational Rehabilitation/Employment	4, 6, 7, 16, 17
Increasing Fistulas	15
Immunizations	5, 6, 8, 13, 17

Area of Care	Networks
Transplantation	4, 5, 6, 11, 14, 15
Continuous Quality Improvement / Quality	3, 5, 9, 14, 15, 17
Pediatric Dialysis	1
Early Referral / Early Renal Insufficiency	5
Hepatitis B and / or Hepatitis C	4, 12, 16, 18
CPMs, including Quality Measuring and Reporting, Physician Activity Reports, and Profiling Reports	1, 2, 3, 5, 7, 8, 9 / 10, 11, 13, 16
Centers for Disease Control & Prevention (CDC) Annual Survey	1, 3, 5, 8, 11, 13, 15, 17, 16, 18
Quality Awards	5, 17
Electronic transmission of laboratory data (Elab)	1, 5, 6, 8, 11, 14
Common Practices	6
Knowledge Management Program	1, 5
Pediatric Project	1, 4
Home Dialysis	3, 15
Mortality – Standardized Mortality Ratios	16
Internal Quality Program	5, 15, 17
Amputation	8
Challenging Patients	8, 11, 14, 17

Source: Networks 1-18 Annual Reports, 2001

PROVIDE PROFESSIONAL EDUCATIONAL MATERIALS AND WORKSHOPS FOR FACILITY STAFF

The principles of quality improvement compel the healthcare team to identify opportunities for improvement and develop appropriate interventions. ESRD Networks are a vital resource to facilities, providing educational materials and workshops. Under contract to CMS, Networks are to provide, at a minimum, the following materials:

1. ESRD Network goals, the Network activities conducted to meet these goals, and the Network's plan for monitoring facility compliance with goals;
2. The Network's Annual Report;
3. Regional patterns or profiles of care as provided in the Clinical Performance Measures Annual Report;
4. Results of Network Quality Improvement Projects;
5. Other materials (such as journal articles or pertinent research information) that providers/facilities can use in their quality improvement programs;
6. The process for handling patient grievances;
7. Treatment options and new ESRD technologies available for patients; and,
8. Information about state/regional vocational rehabilitation programs available in the Network area.

The Networks develop materials, as well as serve as a clearinghouse for materials developed by others. A variety of communication formats and vehicles are used to disseminate these materials including hard copy, Network website postings, electronic mail, and broadcast fax. Some of the professional workshops and educational sessions offered by Networks are highlighted in the table below by general topic: clinical, continuous quality improvement, patient-related issues, communication/crisis management, general, and psychosocial/rehabilitation. A more detailed explanation, by Network, is included in Appendix O.

Table 10

HIGHLIGHTS OF PROFESSIONAL EDUCATION MATERIALS/WORKSHOPS PROVIDED BY NETWORKS

TITLE	TYPE
Clinical	
The Use of Erythropoietin Prior to the Initiation of Dialysis and Its Impact on Mortality in New ESRD Patients	Workshop
Ethics Workshop	Workshop
Nutrient Status Assessment-Emphasis on Surface Anatomy Change	Workshop
Women's Health Issues in Renal Disease	Workshop
Role of Medical Directors Dealing with Non-compliant/Abusive Patients	Workshop
Knowledge Management Program	Newsletter
Outpatient Diabetes Self-Management Training Program	Workshop
Vascular Access Management Symposium	Workshop
End of Life Issues	Workshop
Management of Patients with Diabetes on Dialysis	Workshop
Recommendations for Preventing Transmission of Infections Among Chronic Hemodialysis Patients (2001, CDC)	Brochure
Network Patient Care Technician Educational Workshops	Workshop
Nephrology Nurses' Role in the Care of the Patient with Chronic Kidney Disease	Workshop
CQI	
Ensuring Safe Water for Hemodialysis (Zyzatech Water Systems)	Workshop
Iron Update (Watson Pharmaceuticals)	Workshop
The Memory Jogger	Brochure
Water Treatment Seminars (2)	Workshop
Hemodialysis Access Failure -- A CQI Approach	Brochure
Quality Assurance/Improvement Manual	Manual
Patient-Related Issues	
Partnering With Patients	Workshop
Non-Compliant/Abusive Patient Manual	Booklet
Caring for Patients with Special Needs	Manual
Recommendations for the Management of Disruptive and Abusive Patients	Brochure
Prepared Beginnings and Endings	Workshop
2001 Red Book on Employment Support (SSA)	Booklet
A Guide to Plans for Achieving Self-Support (SSA)	Booklet
Understanding and Using Services of the Office of Vocational Rehabilitation: A Guide for Professionals	Brochure

Care of the ESRD Patient	Workshop
Spring & Fall Mentoring Workshop Series (Held in Arkansas, Louisiana and Oklahoma)	Workshop
Clinic Workshops on Patient Sensitivity	Workshop
Protocol for the Evaluation of Patient Concerns and Grievances	Brochure
Communication/Crisis Management	
Crisis Prevention Training	Workshop
Practical Skills for Recognizing, Addressing, and Resolving Conflict and Violence in the ESRD Setting	Workshop
Birmingham Project	Workshop
The Impact of Conflict on Patient Care	Workshop
Role of the Network and Conflict Resolution	Workshop
ESRD Network Treatment Agreement Guide: Guidelines and Resources to Improve Communications and Develop Expectations Between Renal Professionals and Their Renal Patients	Brochure
"Communication, Conflict and Mediation in the Dialysis Setting"	Workshop
Disaster Preparedness for Dialysis Facilities	Booklet
General	
Emergency Preparedness Manual	Booklet
Vascular Access in the New Millennium	Workshop
Sensitivity Training for Dialysis Unit Staff - nine sessions	Workshop
Training Programs for Facility Data Contacts (3)	Workshop
Vocational Rehabilitation	Workshop
Disaster Preparedness	Workshop
Explanation of the Role of the Network	Workshop
"ESRD Patient Safety Toolkit"	Toolkit
What is an ESRD Patient (OVR Training Booklet)	Booklet
Patient Information for GED Testing	Brochure
An Introduction to ESRD Patient Safety	Workshop
Network 101	Workshop
Psychosocial/Rehabilitation	
Reducing Conflict & Improving Communication	Workshop
Unit Self-Assessment Manual for Renal Rehabilitation (USAT)	Booklet
How to Develop an Exercise Program -- One Unit's Approach	Workshop
Implementing an Exercise Program in Your Dialysis Unit – A Program from the Network 4 Rehabilitation Committee	Booklet
Psychosocial Considerations for ESRD Surveyors	Workshop
Presentation on Psychosocial Issues of Families	Workshop
Other	
How Data Submission Affects the Renal Community	Workshop
Successful Interventions for Increasing the Availability of Organs for Transplantation	Workshop
Forum Medical Record Model	Letter
Professional Ethics Education for Social Workers	Workshop
Early Renal Insufficiency	Booklet
Tenderizing Tough Issues	Workshop
Position Statement on Universal Precautions for AIDS/HIV Disease	Brochure

Model Treatment Agreement	Letter
Hepatitis B Resource Guide	Brochure

Source: Networks 1-18 Annual Reports, 2001

In addition to the professional educational sessions offered to facility personnel and the educational materials distributed, several Networks published journal articles, displayed posters, and gave presentations at professional meetings during 2001. A list, by Network, is provided in Appendix P.

PROVIDE PATIENT EDUCATIONAL MATERIALS AND WORKSHOPS TO FACILITIES AND DIRECTLY TO PATIENTS

ESRD Networks also develop and serve as a clearinghouse for patient education materials. Some materials are sent directly to patients, while others are distributed to facilities for use in patient education efforts. All Networks have toll-free numbers for patients and respond to numerous requests for patient assistance.

Many Networks utilize Patient Advisory Committees (PACs) and/or patient representatives at the facility level to gather patient concerns and distribute information. All Networks use a variety of media and dissemination methods to provide patients with information such as: meetings, teleconferences, direct mailings, booklets, posters, brochures, videos, training manuals, and website updates with items of interest to patients. Several Networks publish newsletters for patients (e.g., Patient REMARCS, Renal Health News, The TransPacific Renal Newsletter, Lone Star Newsletter, Renal Roundup, Network News, Renal Outreach, Kidney Koncerns, Common Concerns, Nephron News and You). Network personnel present information at conferences and participate in patient programs sponsored by other renal-related organizations (such as area transplant and dialysis support groups, civic organizations and church groups, NKF Patient Education Seminars, AAKP, community awareness seminars, and patient services symposiums).

Highlights of patient educational offerings during 2001 are provided below in Table 11. A more detailed explanation, by Network, is included in Appendix Q.

Table 11
HIGHLIGHTS OF PATIENT EDUCATION MATERIALS/WORKSHOPS PROVIDED BY NETWORKS

TITLE	TYPE
Access	
What is Your Access-Ability? (translated into Spanish)	Brochure
Adequacy of Dialysis	
PD Adequacy	Video
Vascular Access for Hemodialysis	Video
Other Clinical Issues	
Choosing the Right Treatment for You	Brochure
"What is Adequate Dialysis?"	Video

Network 8 Modality booklets	Booklet
AAKP brochures on Iron, Protein and Calorie Counter; and Na-K-Phos	Brochure
Communication & Psychosocial	
Our Focus is on You! A Patient Workshop	Workshop
Workshops for patient support groups on negotiation, communication, crisis prevention, and sexuality	Workshops
Diet & Nutrition	
Renal Osteodystrophy & Dietary Issues	Workshop
Boy, Food Doesn't Taste As Good As It Used To. An Explanation of Some of the Reasons for a Diminished Sense of Taste	Brochure
Disaster/Emergency Preparedness	
Emergency Preparedness Resource for PA & DE Patients	Brochure
Preparing for Emergencies: A Guide for People on Dialysis (CMS)	Booklet
Disaster Preparedness for Persons on Dialysis & Transplant Recipients	Brochure
General	
Meeting the Kidney Challenge	Brochure
Statement of Patient Rights and Responsibilities (available in both English and Spanish)	Brochure
Footcare for Diabetic Patients	Brochure
Influenza Vaccination Information	Brochure
Patient and Family Conference	Workshop
The ABCs of End Stage Renal Disease, A Patient Workshop	Workshop
Living with Kidney Failure, A Patient Manual	Manual
Living Well on Hemodialysis	Video
Life Goes On…After Your Kidneys Stop Working	Book
Patient Meetings at the Clinic	Workshop
Beat the Bug: Simple, Proven Strategies to Reduce Flu and Pneumonia Illnesses	Brochure
Advance Health Care Directive Act - A Guide for Chronic Dialysis Patients	Brochure
An Itching Problem: Some Successful At Home Remedies for the Itching Associated with Renal Failure	Brochure
Religious Faiths and Transplantation	Brochure
Right of Patients to Change Physician or Facility	Brochure
Medicare Supplement Handbook	Brochure
Grievances & Patient Concerns	
Network 4 Patient Rights and Responsibilities/Grievance Procedures	Brochure
What are My Options if I have a Grievance?	Brochure and posters
Treatment Options/Transplant	
Organ Donation Poster Contest	Poster

Vocational Rehabilitation / Employment / Finances / Exercise	
Special Vocational Rehabilitation Pilot Project (CMS NW02-01)	Workshop
Exercise Programs in Dialysis Units	Workshop
Exercise Demonstration Project	Workshop
Employment and Rehabilitation	Workshop
Understanding and Using Services of the Office of Vocational Rehabilitation: A Guide for Patients	Brochure
"Dialysis Workout"	Video

Source: Networks 1-18 Annual Reports, 2001

Beginning in the fourth quarter of 2000, new ESRD patients were sent a package of orientation materials. This was accomplished through a collaborative effort between the Networks, CMS, and the Forum Clearinghouse. New patients are identified upon entry into the Network data system (via the CMS 2728 Form). Mailing labels are generated and provided to a mailing service for distribution to patients. In 2001, a total of 90,706 new patient orientation packets were distributed. The package of orientation materials was revised in Year Two (October 2001) of the project to include:

- A Medicare beneficiary letter from the administrator of CMS
- A letter from the Network Executive Director
- "Medicare Coverage of Kidney Dialysis and Kidney Transplant Services" (CMS booklet)
- "Preparing for Emergencies: A Guide for People on Dialysis" (CMS booklet)
- "AAKP - Patient Plan, Phase I " (AAKP booklet)
- "The Voice The Home The Hope" (NKF brochure)
- "AAKP Resources" (AAKP Brochure)
- "Dialysis Facility Compare" (CMS Brochure)

In 2002, the newly developed CMS booklet "You Can Live" will be incorporated into the packet in place of the AAKP booklet. The rate of package return was tracked, and the data shows small variation between Networks, and indicated that the vast majority of packages, 96%, were delivered.

OFFER TECHNICAL ASSISTANCE TO DIALYSIS AND TRANSPLANT FACILITIES

ESRD Networks provide technical assistance to the personnel of dialysis and transplant providers on an ongoing basis as part of their daily operations. In order to respond to the technical needs of the renal community appropriately, Networks employ qualified personnel with expertise in dialysis and transplant nursing, renal social work, patient advocacy, healthcare quality, and data management. Technical assistance is provided using a variety of vehicles and venues, including (but not limited to) telephone consultation, on-site visits, meetings, distribution of materials, referral to individuals with additional expertise in the area queried, conference calls, and educational workshops (described in a previous section). If multiple queries are received on one topic, an educational offering or other activity may be conducted to address the issue with a broader audience.

The functionality of SIMS and its expanded capability to enter "contacts" pertaining to issues other than patient concerns and grievances has enhanced the Networks' ability to track the nature of technical assistance provided, as well as the time required. An overview of issues referred to Networks for advice and assistance during 2001 is provided below. (This list is only an overview, and in no way represents all of the issues addressed by every Network during 2001.)

- Advance directives
- Anemia management
- CQI tools and techniques
- Developing facility quality programs
- Dialysis and transplant center reviews
- Disaster planning – post 9/11/01
- Disclosure of HIV status of patients visiting or transferring to other dialysis facilities
- Disruptive and abusive patients
- Duties and tasks for patient care technicians
- FDA safety alerts
- Federal regulations and conditions of coverage
- Infection control issues
- Isolation for VRE
- K/DOQI Guidelines
- Latex allergies
- Low serum potassium dialysate
- Medical records (content and retention)
- OSHA pending needlestick regulations for 2001
- Reimbursement for EPO and iron supplementation
- Roles and responsibilities for Medical Directors
- Staffing recommendations
- Tracking outcome data to detect trends/changes
- Urokinase restrictions
- Water testing requirements

GOAL TWO: IMPROVING DATA REPORTING, RELIABILITY, AND VALIDITY BETWEEN ESRD FACILITIES/PROVIDERS, NETWORKS, AND CMS

Information management is a core function of the ESRD Networks. They routinely collect, validate, and report patient and facility-specific data for many uses:

1. Establish a national surveillance system of ESRD patients to record demographic information and to follow each patient's care through changes in modalities and providers;
2. Profile areas of patient care in need of improvement and support these improvement activities;
3. Identify regional trends in quality to be addressed by the local Network;
4. Provide CMS and other agencies with data necessary for operational activities and policy decisions;
5. Supply data and/or support to the USRDS and other research organizations; and,
6. Report to the renal community on the trends in ESRD care.

Networks established their individual registries in the early 1980s with similar components and definitions. In 1997, the Networks began the complex transition to the national Standard Information Management System (SIMS). The Southeastern Kidney Council (Network 6), on behalf of the Forum and under contract with CMS, leads this project. The project was launched in December 1999 to ensure all Networks had a Y2K- compliant system.

In the fall of that year, all Networks were asked to convert at least five years of data from their legacy system, using the new standardized definitions. When possible, Networks converted their entire system. Using each of these converted datasets, SIMS created the central repository of all patients nationally. As data was added to the repository, thorough checks were run to match patient records from one Network to another in cases where patients had been treated in multiple Networks. Although the system was launched at the end of 1999, Networks worked throughout 2000 to reconcile data to the new structure. CMS began requiring all Networks to use SIMS in July 2000.

Data are now replicated nightly to the central repository. If a patient crosses Network boundaries for treatment, his/her pertinent data are automatically replicated back to the receiving Network. This allows Networks to track patients through the continuum of care and keep accurate records of patients. Some data are not replicated and remain only on the local Network server. Most notably, patient grievance calls and facility staff information are not stored on the repository and are only accessible to the Network that entered it.

Five Major Components of SIMS

Patient Data

- 2728 Medical Evidence form – enters patient in registry and establishes patients benefits for Medicare
- 2746 Death Form – filled out when a patient dies (terminates benefits)
- Patient Events – modality shift, transfer in or out of a provider, transplant, discontinue, recover function, etc. that a patient has during their course of treatment
- 2744 Facility Survey – reconciliation of the patient events that is performed once a year for all facilities

Provider and Personnel

- Facility files housing data on providers including address information, name, affiliation, certification dates, services offered, shift information, etc.
- Personnel files contain data on the majority of personnel at the facility level. Also tracks Network board members and other entities that need to be on mailing lists

Contacts

- Any complaint, inquiry, grievance, or concern coming in from any patient, provider, family member, or member of the renal community

Reports (all exportable for customization of the data presentation)

- Annual reports (incidence, prevalence, transplants, etc)
- Quarterly reports (form counts and some portions of the contacts reporting)
- Listing of providers, their staff, and services
- Miscellaneous reports

Utilities

- Data Cleanup utilities to verify and validate data
- Export files for REBUS for monthly 2728 and 2746 transmission
- CPM patient population files
- CMS output files including a Termination Candidate file, patient census files and current patient status file
- Administrative utilities (mailing label export, internal reports)

Network 6 continues to support SIMS, including system enhancements, hardware and software acquisitions, training, and user support through a help desk. Each month SIMS hosts a two-hour conference call with Networks and CMS to discuss pertinent issues and changes. Networks may recommend additional elements or functionality be added to the system via a Position Paper. Each Network is allowed to comment on the position and if it receives sufficient support, the item will be added to SIMS. In 2001, position papers included:

- 2001-01 Personnel Title
- 2001-02 Standard Facility Services
- 2001-03 Standard Facility Affiliations
- 2001-04 Optional Transplant Text Box
- 2001-05 No Outpatient Dialysis Facility
- 2001-07 ProvNum FacCode Protection
- 2001-08 Auto BicNum Update
- 2001-09 Facility Manager

Currently in SIMS there are over 1 million unique patients and over 3 million patient events for those patients. Some of this information is collected via CMS forms, the 2728, Medical Evidence Form and the 2746, Death Notification. Patient events and other information are collected via Network-defined forms. At night, the CMS forms and patient events are replicated to the central repository for inclusion in the Renal Beneficiary Utilization System (REBUS). Table 12 shows the number of forms transmitted to CMS in 2001.

Table 12
DATA FORMS PROCESSED
Calendar Year 2001

Network	Medical Evidence (CMS 2728)	Death Notification (CMS 2746)	Total
1	4,054	2,886	**6,940**
2	6,583	5,388	**11,971**
3	3,051	3,577	**6,628**
4	5,222	3,626	**8,848**
5	6,336	4,321	**10,657**
6	8,115	5,251	**13,366**
7	6,227	4,395	**10,622**
8	5,236	3,710	**8,946**
9	8,057	5,247	**13,304**
10	4,443	2,838	**7,281**
11	6,895	4,633	**11,528**
12	4,198	3,164	**7,362**
13	4,188	3,322	**7,510**
14	7,851	4,842	**12,693**
15	4,471	2,976	**7,447**
16	2,939	1,875	**4,814**
17	5,007	3,163	**8,170**
18	7,410	3,752	**11,162**
Total	**100,283**	**68,966**	**169,249**

Source: Networks 1-18 Annual Reports, 2001

In building this information infrastructure, the Networks hope to better pursue initiatives to measure and improve the quality of healthcare delivered to the ESRD patient population. The ultimate goal of SIMS is to improve the quality of care delivered by making ESRD data more accessible to dialysis facilities, Networks, and the renal community.

Additional information regarding the SIMS project and all deliverables is available to CMS and the Networks at http://www.simsproject.com.

GOAL THREE: ESTABLISHING AND IMPROVING PARTNERSHIPS AND COOPERATIVE ACTIVITIES AMONG AND BETWEEN ESRD NETWORKS, QUALITY IMPROVEMENT ORGANIZATIONS, STATE SURVEY AGENCIES, AND ESRD PROVIDERS/ FACILITIES

Networks are actively involved with both quality-related and renal-related organizations to facilitate cooperation and joint ventures. Each Network creates unique partnerships with organizations to help provide better care for the ESRD patient population, including renal groups, professional organizations, dialysis corporations, and pharmaceutical companies.

All of the 18 Networks provide support and leadership to the Forum of ESRD Networks. Network MRB Chairs and Board members, Executive Directors, and other staff members assist the Forum by volunteering for positions on the Forum Clearinghouse Board of Directors as well as serving as Forum representatives on various committees such as the National Patient Safety Foundation (NPSF) Steering Committee, National Quality Forum (NQF), Clinical Performance Measures (CPM), and the CMS/Forum Steering Committee.

With participation from all 18 Networks, the Forum Clearinghouse continues to be instrumental in developing and promoting a number of national initiatives to improve partnerships within the Network program and renal community. These include the SIMS initiative; the semi-annual meetings of MRB Chairs; implementation of a strategic plan; quarterly conference calls for Executive Directors, Quality Improvement Directors, and Patient Services Coordinators; and distribution of clearinghouse materials to all Networks.

The 2001 CMS/Forum of ESRD Networks' Annual Meeting "From Accountability to Quality" drew representatives from CMS, Networks (data, quality, patient services, and executive staff), as well as many Network Medical Review Board Chairs to discuss issues impacting the ESRD Networks. Other new activities in 2001 included the development of a patient safety initiative, Phase I in the ESRD Program, reinvigorated partnerships with renal community members such as NKF and AAKP, and the updating of the New Patient Orientation Packet materials for Year Two of the project.

Networks continue to develop relationships and partner with the Quality Improvement Organizations (QIOs, formerly Peer Review Organizations or PROs) to improve the care received by ESRD beneficiaries.

Networks communicate with State Survey Agencies (SSAs) through the exchange of newsletters, annual reports, and other appropriate quality reports. This communication helps to facilitate the exchange of ideas on issues of quality improvement and patient grievances. Networks also work with their constituent State Survey Agencies in resolving patient grievances and assisting facilities in resolving performance issues.

The table below provides a summary of collaborative activities that Networks conducted in conjunction with their area QIOs, SSAs, and the renal community during 2001.

Table 13
NETWORK COLLABORATIVE ACTIVITIES IN 2001

Network	Organization	Topic or Project Name	How This Improves Care
QIO COLLABORATION			
1	Qualidigm (CT QIO)	Reduction in Catheter Reduction	Avoid infections and reduce access complications.
2	Island Peer Review Organization (IPRO)	World Trade Center Attack and Access to Care	Control center established after CMS Region 2 office closed. Assisted in patient relocation, transportation, providers list, emergency preparedness plans.
4	Keystone Peer Review Organization (KePRO)	Early Referral to Nephrology Care Quality Improvement Project (QIP) for 1998-1999	The project reviewed outcomes of patients referred to nephrologists prior to the initiation of dialysis as compared to those patients who presented for emergent treatment. CMS claims data were reviewed to determine a difference in cost and efficiency. It was expected that differences would occur based on access procedures that would coincide with entry into dialysis. The goal of this project was to quantify the impact of early referral on morbidity, mortality, and cost. A conference call was held with KePRO and Network staff on 8/21/01 to review the project design and identify "lessons learned" from this type of collaboration. Both parties believed the project was planned and designed well with several face-to-face meetings and conference calls. Tasks were equally divided throughout the project. Important considerations for future projects were identified.
4	Keystone Peer Review Organization (KePRO)	Influenza Immunization Quality Improvement Project (QIP) for 1999-2000	The Network accepted the suggestion of the Boston Regional Office to extend this QIP. Goals included: increase the proportion of ESRD patients in NW 4 informed about the medical benefits offered by influenza vaccination; increase the proportion of patients receiving an influenza immunization; increase the proportion of NW 4 dialysis facilities that document immunization status of each patient; increase the proportion of facilities that receive information about the importance of immunization for ESRD patients; increase the proportion of facilities that receive information about Medicare coverage and roster billing for immunization administration; and increase the proportion of facilities that offer a preventive immunization program in the unit. Educational materials, obtained again from KePRO, were sent to the facilities in 2001 for both staff and patients. By facility record documentation, 77% of the patients were immunized in 1999-2000 and 80.3% were immunized in 2000-2001.
4	Keystone Peer Review Organization (KePRO)	The Executive Director served on KePRO's Steering Committee.	Facilitates the sharing of information, including ongoing QI projects.
5	West Virginia Medical Institute (WV QIO)	Annual Flu Shot Campaign	Encourages patients to receive preventive care (flu shot).

5	Virginia Health Quality Center (VA QIO)	Annual Flu Shot Campaign	Encourages patients to receive preventive care (flu shot).
5	Virginia Health Quality Center (VA QIO)	Contracts to provide project design and statistical services for the PD Adequacy QIP, the 2nd QIP on HD Adequacy, and the Vascular Access-Catheter Reduction QIP	Creates a stronger project to detect what interventions actually result in increased adequacy values and in reduction of catheter rates.
7	Agency for Health Care Administration (AHCA)	Information on profiles and patterns of care and outcomes to be used in ESRD Medicare survey and certification activities: referred patient and professional complaints and participated in an on-site investigation, technical assistance on issues such as water treatment, reuse, isolation practices, HIV, and professional requirements and development and implementation of disaster plans.	Better serve the patients in the state.
8	Alabama QIO	Safety Initiative	This initiative was designed to develop a common system for identification and classification of adverse events in the ESRD setting.
8	Tennessee QIO	Lower Extremity Amputation Project (LEAP)	Involves facility monitoring of ESRD patients' foot care to reduce amputations in this population.
9	Health Care Excel (Kentucky and Ohio)	The Network is represented on cooperative committees organized by Health Care Excel.	
9	KePRO, the contractor for the peer review organization for the State of Ohio	Study of cardiac risk factors in dialysis units in Northeast Ohio.	
13	Louisiana QIO	Adult Immunizations for ESRD Patients	Increasing the percentage of immunizations should reflect in lower numbers of people dealing with the complications of influenza, pneumococcal pneumonia, and hepatitis.
13	Oklahoma QIO	Lower Extremity Amputation Project	Increasing the number of foot exams performed should ultimately decrease the number of amputations performed secondary to complications of diabetic neuropathy.
14	Texas Medical Foundation	Partnership to educate ESRD patients and professionals about the importance of receiving recommended vaccines during the fall and winter months.	

15	Mountain Pacific Quality Health Foundation (MPQHF) in Wyoming	Alternative settings project focused on immunization in the ESRD population; collaboration on follow-up data collection was completed in March 2001 and a poster presented at the annual Forum/CMS meeting.	
15	Colorado Foundation for Medical Care (CFMC)	Collaborated on producing a training video in a dialysis facility for training on use of facility-specific outcomes measures for the survey process.	
16	Multiple	Mini Team Meeting conference calls	Organized by the CMS Central Office to bring together QIOs that were conducting quality improvement projects in the ESRD community with the Networks in the affected regions. The purpose of these calls was to create a forum where QIOs and Networks could share their experiences working with ESRD providers and consumers.
16	Colorado Foundation for Medical Care	Colorado Foundation for Medical Care's Pilot Test project: ESRD Facility Specific Profiles for State Survey Agencies	Network staff reviewed project materials and helped to refer questions from staff at individual facilities to the appropriate contact persons at CFMC.
18	California Medical Review, Inc. (CMRI)	Influenza vaccination	Based on available data, influenza vaccination rate improved nearly 50% and the project will be renewed again in 2002.
STATE SURVEY AGENCY COLLABORATION			
4	Pennsylvania and Delaware State Department of Health Agencies	CMS, Networks, and SSA Meeting, March 21, 2001	Establishing working relationships.
5	Virginia State Survey Agency	Information sharing & collaboration between the Network and State Survey Agencies	Assistance in resolving grievances and addressing quality of care concerns at the facility level promotes better utilization of resources.
7	Agency for Health Care Administration (AHCA)	Memorandum of Understanding	
11	Michigan Department of Consumer and Industry Services	Pilot project to improve the patient complaint system	Coordinates Network and state survey agency efforts; improves responsiveness and communication; focuses resources
15	AZ, CO, NV, NM, UT and WY State Survey Agencies	Information Sharing and Collaboration	Assistance with technical questions, grievance resolution, and CQI issues.

16	Oregon	Network Executive Director served on the Oregon State Health Care Licensing and Certification Health Division's Task Force to develop administrative rules for the licensure of dialysis facilities.	
16	Washington State Department of Health	Certificate of Need Program	Network provided patient profile data and facility treatment volume data for use in review of certificate of need applications for new and/or expanded ESRD services in Washington.
17/18	California Medical Review Inc.	Flu Campaign to promote increased immunization for the ESRD population.	Educate facilities and patients about the importance of yearly flu vaccinations.
17/18	California Department of Health Services (DHS)	Network participated in CMS/DHS surveyor training sessions.	
17/18	California Department of Health Services (DHS)	A sentinel event reporting system has been implemented with the Standards of Care Project. Sentinel events in facilities will be reviewed by the MRB and forwarded to the DHS if necessary.	With the advent of a reporting system, it is anticipated this data can be analyzed, trended, and reported to facilities to assist them to work to improve circumstances that may be preventable and improve patient care.
RENAL COMMUNITY COLLABORATION			
5	NKF (West Virginia & Washington, DC chapters)	Network collaborated in conducting Chapter symposiums	Provides educational and networking opportunities for renal professionals.
5	Partnerships with Corporate Chains	Three (3) corporate dialysis chains provide treatment to almost 70% of Network 5 patients. Therefore, in 2000 a strategic effort was launched to meet with representatives from the corporate chains on an on-going basis. Two meetings were held in 2001 and the agenda focused on: Early Renal Insufficiency Programs, Quality Awards to facilities, information released to SSAs, and Network 5's Information Management Policy. Meeting evaluations showed positive responses.	The purpose of partnering with the dialysis corporations is to better utilize resources of both dialysis chains and Networks by jointly addressing issues of mutual concern, such as improved patient outcomes and engaging physicians.
5	Gambro Healthcare; DaVita; Fresenius Medical Care	Conducted crisis prevention training sessions for facility staff.	Increases staff knowledge and skills in recognizing, de-escalating, and/or handling crisis situations (such as violent or abusive patients).

8	Gambro and NNA	Network 8 coordinated development of a protocol to address displaced patients.	Training of nurses, social workers, and PCTs was provided in an effort to teach observance of professional boundaries and de-escalation of potentially violent situations.
13	NKF of Oklahoma	A National Conference	Addressing the treatment of kidney disease with the American Indian population.
14	Texas Rehabilitation Commission (TRC)	Network provides Texas Rehabilitation Commission Counselors with information on causes of ESRD, treatment of ESRD, ESRD Vocational Rehabilitation Data, initiatives to increase ESRD vocational rehabilitation, and recommendations to improve referral process between facilities and TRC.	
15	NKF-CO and AZ chapters	Educational sessions and collaborative meetings.	
15	ANNA Chapters (CO, NV)	Partner for educational presentations.	
16	Alaska, Idaho, Montana, Oregon, Washington state agencies	Monthly conference calls convened by CMS Project Officer.	Network staff, CMS Regional Officer, and State Agency representatives continued their monthly conference calls. These meetings improve inter-agency information exchange and identify areas of mutual concern.
OTHER COLLABORATION			
5	Harvard School of Public Health	Promoting Living Donor Transplant Through Increased Educational Effort	Increase number of patients receiving (or referred for) living donor transplant.
5	Ortho-Biotech	Recognition & Management of Early Renal Insufficiency (ERI)	Improve outcomes and decrease mortality/morbidity among new dialysis patients by improving their care management during the ERI/pre-ESRD phase.
5	Network 1	Knowledge Management Program	Supports internal quality efforts by providing information to nephrologists using push technology.
5	Virginia Academy of Family Physicians	Assisted in conducting annual meeting	Promotes interaction between PCPs and renal professionals and increases knowledge regarding recognition and management of ERI.
5	Virginia Commonwealth University's School of Nursing	Workshop on Ethics in Dialysis	Increases awareness about the issues and provides resources and information to address the dilemmas.

Source: Networks 1-18 Annual Reports, 2001

Networks actively seek partnerships and conduct activities with renal-related organizations and quality associations, and have also have forged relationships with advocacy and research organizations. Several of the organizations that Networks worked with during 2001 are listed below.

Renal Community	Non-Renal Related
• American Association of Kidney Patients • American Kidney Fund • American Nephrology Nurses Association • American Society of Nephrology • Life Options Rehabilitation Advisory Council • National Kidney Foundation • National Renal Administrators Association • Nephrology Pharmacy Associates • Renal Physicians Association • Polycystic Kidney Foundation • United Network for Organ Sharing • United States Renal Data System • Six major Corporate Dialysis Chains	• American Society of Quality • American Healthcare Quality Association • Association for Advancement of Medical Instrumentation • Centers for Disease Control and Prevention • Food and Drug Administration • Harvard School of Public Health • National Association for Healthcare Quality • National Quality Forum • Rand Corporation • Institute for Healthcare Improvement

Many of the ESRD Network personnel are actively involved on renal community boards of directors and committees. The following are some of the organizations in the renal community with whom Networks serve on boards and committees: National Kidney Foundation (NKF), the American Association of Kidney Patients (AAKP), the American Nephrology Nurses' Association (ANNA), the Renal Physicians Association (RPA) and NIDDK's National Kidney Disease Education Program (NKDEP).

GOAL FOUR: EVALUATING AND RESOLVING PATIENT GRIEVANCES

Networks are responsible for evaluating and resolving patient grievances. Each Network has a formal grievance resolution protocol, approved by CMS. The Network's ESRD Manual outlines several examples of the Network's role in resolving patient grievances. These include:

- **Expert Investigator:** This involves evaluating the quality of care provided to a patient where the investigation focus is the complaint. For example, if a patient complains about the procedures used by the dialysis nurse to initiate dialysis, the Network may investigate by reviewing the techniques used by the facility to initiate dialysis. At the conclusion of the investigation, findings are shared with the involved parties and when appropriate, recommendations may be made about the care provided.

- **Facilitator:** When communication between the patient and the provider/facility is difficult, the Network may be asked to facilitate communication and resolve the differences. For example, a patient may contact the Network to complain that the facility hours do not accommodate his/her work schedule. The Network may assist the patient by helping to discuss the situation with facility personnel or assist the patient in moving to another facility that can accommodate his/her needs.

- **Referral Agent:** Issues that are not specifically ESRD Network issues such as fire safety, handicap access to dialysis, civil rights, infectious disease and criminal activity are more appropriately handled by either the State Survey Agency or other federal agencies. The Network may refer the beneficiary to the appropriate agency.

- **Coordinator:** Where both quality of care and survey and certification issues are involved (e.g., water quality or dialyzer reuse), the Network will coordinate the investigation with the appropriate State Survey Agency. The appropriate Regional Office is advised of the situation.

- **Educator:** When patients, families, or facility staff have questions regarding ESRD, the Network may provide the information. If the Network is not readily able to provide the education, the Network is able to refer the question to the appropriate source.

A formal beneficiary grievance is a complaint alleging that ESRD services did not meet professional levels of care. The formal grievance requires the Network to conduct a complete review of the information and an evaluation of the grievance, which may require the involvement of a Grievance Committee and/or the Medical Review Board. During 2001, Networks processed 70 formal beneficiary grievances.

Grievances come to the Network in many forms and from many sources including telephone calls and letters from patients, families, facilities, and concerned individuals or agencies. Though many of these complaints never reach the formal grievance stage, Networks dedicate large amounts of staff time responding to these complaints. It is estimated that ESRD Networks process over 7,000 such patient concerns annually. The relatively small proportion (less than 1%) of formal beneficiary grievances is an indication of effective Network response to the complaint before it escalates into a formal grievance.

During 2001, Networks spent time discussing and focusing on "challenging situations." A number of Networks define the challenging patient as one who may present to a clinic and act out in a violent manner or who is verbally abusive or threatening. Each Network has a social worker/patient services coordinator to conduct proactive work in this area. Many Networks continue to provide workshops and written material focusing on this issue and spend a great deal of staff time providing consultation to the clinics in an effort to support a safe environment for patients and facility staff. An effort is underway within the Networks to gain a greater understanding of this issue and to quantify its prevalence.

Table 14 displays the number of Formal Grievances processed in the year 2001. The Networks realize the importance of standardizing the language and understanding of the types of grievances. A work group is collaborating on definitions and reports to be used in SIMS (Standard Information Management System).

Table 14
Formal Grievances Processed
Calendar Year 2001

Network	# of Grievances	Network	# of Grievances
1	0	**10**	15
2	2	**11**	0
3	0	**12**	10
4	0	**13**	0
5	12	**14**	5
6	1	**15**	0
7	6	**16**	0
8	2	**17**	0
9	12	**18**	5
TOTAL = 70			

Source: Networks 1-18 Annual Reports, 2001

Table 15 details the types of grievances handled with an example for further clarification of the grievance.

Table 15
TYPES OF GRIEVANCES

Type of Grievance	Example/Resolution
Treatment Related/Quality of Care -Any concern relating to the medical treatment a patient receives at the unit.	Primary concern to patients was staffing ratios, turnover, qualifications, and lack of professionalism. Patients were not seen on a regular basis by a nephrologist in the dialysis unit and did not receive a timely response to requests for information and assistance. Network substantiated claims; facility addressed issues.
Physical Environment -Any concern relating to the physical atmosphere. These may include temperature, cleanliness, hazards, etc.	Patient concerns involved environmental issues such as temperature in the unit, aseptic technique, and cleanliness. As necessary, the Network staff contacted the Administrator to request specific documentation for investigation of concern.
Staff/Provider Related -Any concern including difficulties with provider policies or staff professionalism and competency.	Patient's family complained about mistreatment by two patient care technicians who had infiltrated his access upon cannulation and then almost hooked the patient up to the machine before it was done rinsing. The family also had been advised by the nephrologist not to call because he doesn't tolerate disgruntled family members and that he did not have to continue to provide care. The family member was advised to meet with the Administrator.
Information -Any concern that relates to the knowledge base associated with ESRD issues.	Patient contacts were for information about services such as insurance coverage, transportation, or access to care. When appropriate, the names and telephone numbers of agencies or individuals who could assist with the resolution were provided.
Patient Transfer or Discharge -Any concern that relates to the inter-facility patient transfer process.	Network assisted a dialysis facility in obtaining information to complete the CMS 2728 form after a patient had been accepted as a transient patient when, in fact, they were transferred to the facility permanently. The patient had been discharged from a non-renal facility.
Disruptive/Abusive Patient -These concerns, lodged by the facility, focus on how to handle a patient and/or family that is disruptive or abusive.	Networks have seen an increased number of requests for assistance in managing disruptive or abusive patients. Resolution includes review of facility policies and procedures, development of a behavioral contract, and/or advice to contact the police in case of immediate danger.

Source: Networks 1-18 Annual Reports, 2001

Table 16 provides examples of the grievances handled by the Networks. The table cannot completely engender the difficult and complex nature of the cases presented to the Networks on a daily basis, nor can it detail the extensive follow up that is often required to resolve the grievance. The examples are offered to illustrate the types of issues faced throughout the entire country in both rural and urban settings.

Table 16
EXAMPLES OF GRIEVANCES

Contact Type	Description of Contact	Action/Resolution
Physical Environment	Staff received a letter from a patient expressing concerns about the lack of air conditioning at their dialysis facility.	The Network contacted the facility and found that the air conditioning was broken, under repair with part ordered. Fans were brought in to cool the facility. Repair completed within a few days.
Staff Related	Complaint about adequate staffing: nurses, social workers or dietitians.	Facilities have high turnover in staffing. Often upon investigation, the Network finds that staff is hired and/or interim service is arranged.
Treatment Related/Quality of Care	Patient complained that the facility allowed inexperienced staff to "practice" on her graft and caused multiple infiltrations. Staff members were not caring nor concerned about the problems the patient was experiencing with her access.	Complaint was partially substantiated and the facility was required to develop an improvement plan to include: professionalism, complication intervention and appropriate reporting, customer interaction, and dealing with difficult patients.
Information	Inquiries are usually requests for information or educational materials.	Information is supplied or referrals given as appropriate for educational materials for family members and patients new to dialysis, transportation questions, insurance coverage, and requests for list of facilities to obtain transient dialysis treatments.
Disruptive or Abusive Patient	A difficult patient stated that a staff member wouldn't allow him to use the bathroom; he called the nurse " stupid." The patient claimed the nurse had called him stupid and another staff member raised their fist to the patient.	The Network had already been contacted about this patient's behavior problems. The SSA had also been contacted and was unable to substantiate the patient's grievances. He was considered a threat at the facility and arrangements were made for him to transfer to another facility. Staff was counseled and attended Crisis Prevention Workshops.
Patient Transfer or Discharge	Family member of patient called regarding location of facility close to home of patient.	Staff member gave the individual the names of dialysis facilities within a reasonable distance of the patient's home.
Professional Ethics	Complaint that the staff acted in an unprofessional manner when dealing with wheelchair-bound patient, inappropriately with a patient who was bleeding from an access site post-treatment, and there was a consistent two-hour wait for treatment initiation.	MRB recommended that the facility review their internal processes.

Source: Networks 1-18 Annual Reports, 2001

SANCTION RECOMMENDATIONS

Networks are authorized to propose (to CMS) sanction recommendations against facilities who are out of compliance and to make recommendations for additional facilities in the service area, as they are necessary for each particular Network.

During 2001, no sanction recommendations were made to CMS. There were several incidents noted that required Network scrutiny:

- In one Network, a dialysis facility was placed under MRB focused review and the providers showed a high level of cooperation in their attempt to maintain compliance with the CMS regulations and standards.

- One Network provided expert consultation to a State Survey Agency in the investigation of two facilities where quality of care deficiencies had been reported. The facilities were under common management with two other facilities, which closed following State action in 2000. Problems identified by the Network and SSA were adequately addressed by the two facilities and no further action was required.

- During 2001, the State Department of Health identified a facility with serious or life-threatening deficiencies during a survey. The Network MRB reviewed the results of the survey and concurred that the circumstances described by the Department of Health were serious and life-threatening. The practices in the facility over time did not meet the standards of care. The MRB expressed concern for the health and welfare of the patients due to the serious nature of the unmet safety measures common to dialysis procedures in multiple care delivery areas. The MRB recommended facility closure and Medicare decertification. The State Department of Health worked with the facility owners and the facility was voluntarily closed.

- Another Network noted that they provided technical assistance to facilities and/or providers to assist them in meeting the Network/CMS benchmarks for quality care. This collegial model used by the Network ensured that the facilities and/or providers were able to accept the Network and CMS requirements.

RECOMMENDATIONS FOR ADDITIONAL FACILITIES

Several Networks made recommendations in their Annual Reports. These included:

- A shortage of trained dialysis staff continues to prevent outpatient dialysis stations from being fully utilized. In the past two years, the Network worked with CMS and the state to distribute information to state hospitals about using the "special purpose unit" status to relieve this problem of new ESRD patients remaining in the hospital for unnecessary extended periods of time. As the crisis of lack of dialysis nurses increases, the Network is receiving more inquiries from other states about being able to obtain outpatient dialysis within a reasonable travel distance.

- A Medicare assessment of the costs to operate dialysis centers should include regional adjustments for staff wages and local state regulations, which affect operational costs. The increasing number of challenging patients requires unique staff communication and interpersonal skills. Consideration, by CMS, of special dialysis units with additional reimbursement to help accommodate these patients would reduce the number of patients experiencing an involuntary discharge from dialysis units.

- There continues to be an increase in the number of medically stable patients that require a course of short-term dialysis (non-chronic) in out-patient programs, usually requiring less than three months of dialysis. Managed care and shorter in-patient hospital days may have created this new patient group. The Network recommends that CMS develop billing codes

for this patient population and that consideration be given to future policy issues that will evolve as these non-chronic patients increase in number and require short-term outpatient dialysis treatments.

- Though the Network has not formally recommended additional or alternative services or facilities, be advised that the regional State Survey Agency has requested information from the Network regarding need. A number of facilities indicated that they plan to expand their capacity based on utilization data. Inquiries have been received from persons who planned to open new facilities.

- Disruptive or Challenging Patients
    - There is a bona fide need in the ESRD system to address the treatment of patients who have not been accepted by an outpatient treatment facility. The practice of discharging patients that pose a behavioral risk in the outpatient dialysis care setting is steadily increasing. Many patients are well known in the community as a potential hazard to staff and other patients and are discharged from one unit and not accepted into another. This activity leaves the already volatile patient in need of care and in the emergency room to receive hemodialysis. The Network recommends that CMS Study the issues to identify a solution that will provide quality, alternative care for the patient that is not appropriate for the outpatient setting. This review should include representatives from the ESRD and mental health communities. Solutions may include changes to designation of and increased compensation for units staffed to handle challenging patients and other creative responses to this complex situation.
    - A second Network has identified the need for special service facilities that can be adequately staffed and equipped to provide services to a subset of the Medicare patient population that has been labeled disruptive and are being discharged from the chronic facilities without any other chronic facility to provide necessary services. The type of facility would provide services to patients with a history of aggression, mental illness or other needs that are not conducive with services provided at the typical chronic facility and general dialysis population. CMS is aware of this and will need to analyze the cost factors and make recommendations for changes that will make these facilities cost effective so the need will be filled by the private sector.
    - A Network recommends that CMS foster the establishment of special needs dialysis facilities in the major metropolitan areas to serve displaced patients that require chronic dialysis yet do not have a chronic provider. It is anticipated that these special needs facilities would require special services to meet the needs of this increasing population. Establishment of these special needs facilities could be fostered through a CMS-sponsored demonstration project or a waived requirement to justify higher reimbursement rate with historical cost for initial set up of facilities.
    - It is also recommended that CMS convene a national consensus conference to explore this complex issue surrounding the treatment or lack of treatment for challenging ESRD patients.

- One Network has a continuing concern identified by patients from outside the region about a lack of space for visitors (transient dialysis). In addition, due to staffing shortages, some facilities are not able to run at full capacity. This has negatively impacted access to care in some regions of the Network.

- A severe shortage of licensed professional personnel accounts for a waiting list of patients to enter some chronic dialysis facilities. This is a problem of human resources.

- Another Network mentions the staffing shortages, transient and abusive/violent patient issues but also notes that the Network receives inquiries regarding the provision of dialysis services in skilled nursing/long-term care and other non-ESRD certified health care facilities. Inquiries are also received regarding access to care/services for undocumented immigrants whose Medi-Cal eligibility is limited to "emergency services."

FOR MORE INFORMATION

This report summarizes highlights of the ESRD Networks' 2001 activities. The following Internet addresses provide additional information about the ESRD Networks and the ESRD program. All Network web sites can be accessed through the home page of the Forum Clearinghouse Office: http://www.esrdnetworks.org.

Table 17
NETWORK WEB ADDRESSES

Network	Web Address
1	http://www.networkofnewengland.org/
2	http://www.esrdny.org
3	http://www.tarcweb.org/tarcweb/
4	http://www.esrdnetworks.org/networks/net4/net4.htm
5	http://www.esrdnet5.org/
6	http://www.esrdnetwork6.org/
7	http://www.esrdnetworks.org/networks/net7/net7.htm
8	http://www.esrdnetworks.org/networks/net8/net8.htm
9/10	http://www.therenalnetwork.org/
11	http://www.esrdnet11.org/
12	http://www.network12.org/
13	http://www.network13.org/
14	http://www.esrdnetwork.org/
15	http://www.esrdnet15.org/
16	http://www.nwrenalnetwork.org/
17	http://www.network17.org/
18	http://www.esrdnetwork18.org/
SIMS	http://www.simsproject.com/

Table 18
ORGANIZATION WEB ADDRESSES

Organization	Web Address
American Health Quality Association (AHQA)	http://www.ahqa.org/
American Association of Kidney Patients (AAKP)	http://www.aakp.org/
American Nephrology Nurses' Association (ANNA)	http://anna.inurse.com/
Centers for Disease Control and Prevention (CDC)	http://www.cdc.gov/
Centers for Medicare and Medicaid Services (CMS)	http://cms.hhs.gov/
Life Options Rehabilitation Program (LORAC)	http://www.lifeoptions.org/
Medicare	http://www.medicare.gov/
National Association for Healthcare Quality (NAHQ)	http://www.nahq.org/
National Kidney Foundation (NKF)	http://www.kidney.org/
United Network for Organ Sharing (UNOS)	http://www.unos.org/
United States Renal Data System (USRDS)	http://www.usrds.org/

A copy of a specific Network Annual Report can be obtained from the individual Network office or by visiting the Network website linked through the Forum website. Network addresses and telephone numbers are listed on the inside front cover of this Report.

APPENDIX

This document was prepared by the Forum of ESRD Networks Clearinghouse Office, under contract with the Centers for Medicare & Medicaid Services (CMS Contract #500-00-NW14). The contents presented do not necessarily reflect CMS policy.